

NATIONAL HEALTH GOALS

HEARING BEFORE THE COMMITTEE ON LABOR AND HUMAN RESOURCES UNITED STATES SENATE ONE HUNDREDTH CONGRESS

FIRST SESSION

ON

REVIEWING HEALTH CARE PROGRAMS, FOCUSING ON HEALTH PROMOTION AND DISEASE PREVENTION, ACCESS TO ESSENTIAL CARE, REASONABLE PRICES AND REASONABLE COSTS, AND THE ACCESS OF THE ELDERLY TO HEALTH CARE

JANUARY 12, 1987



Printed for the use of the Committee on Labor and Human Resources

U.S. GOVERNMENT PRINTING OFFICE

WASHINGTON : 1987

72-314

For sale by the Superintendent of Documents, Congressional Sales Office
U.S. Government Printing Office, Washington, DC 20402

5541-4

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NATIONAL HEALTH GOALS

MONDAY, JANUARY 12, 1987

U.S. SENATE,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, DC.

The Committee met, pursuant to notice, at 10:06 a.m., in room SD-430, Dirksen Senate Office Building, Senator Edward M. Kennedy (Chairman) presiding.

Present: Senators Kennedy, Hatch, Thurmond, Pell, Simon, Stafford, Cochran, Humphrey, Adams, and Harkin.

OPENING STATEMENT OF SENATOR KENNEDY

The CHAIRMAN. The Committee will come to order.

This is a new Congress, and it marks the beginning of a new era. For several years, the nation has been engaged in a period of retrenchment that has left serious scars on our society.

I believe that the worst is over, and that the nation once again senses its own powers and possibilities; that America is again ready to move ahead.

These hearings, on national goals in health, employment, education and equal opportunity are the first steps toward what this society can achieve by the end of this century.

These hearings will assess where we stand and where we should be heading. In stating facts plainly, I do not intend to indict the past, but to touch a higher instinct, the sense that we have always had at our greatest moments in the past, the belief that America can do better, better than we are now doing, and better than others can do. Americans are ready to face up to the real state of the Union, and to resume the challenge of building this country, a job that never ceases and is never done.

We cannot be complacent when American ranks seventeenth in the world in infant mortality, barely ahead of Cuba. We cannot be satisfied when America ranks fourth in the world in literacy. We cannot rest on our laurels when America is eighty-first in the world in economic growth and when our students are outperformed by their counterparts in other countries, and when our quality of life is below that of most Western European countries. At the present rate, the standard of living in West Germany in 25 years will be twice as high as ours. I say the Centennial Congress must not acquiesce in the continuing decline of the American century.

We must also measure ourselves against our own past. The average 30-year-old American male earns 10 percent less in real terms than his father earned at the same age. The average American family earns less than it did in 1973. We cannot accept a future in

which America is constantly losing ground against its past. We will not settle for a tomorrow in which we become a lesser people in a lesser land.

No cause is closer to my heart than quality health care for all of our citizens. Thirty-seven million of our fellow Americans, including more than 11 million children, lack basic health insurance. Millions of senior citizens, despite the promise of Medicare, are vulnerable to the high cost of catastrophic illness. Dread diseases, including the worldwide epidemic of AIDS, threaten the life and the health of every American.

But these problems are also opportunities. A new consensus is emerging to assure that every citizen has access to the essential health care that constitutes simple justice.

Secretary of Health and Human Services Otis Bowen has already provided courageous and impressive leadership toward the goal of catastrophic health insurance for elderly Americans. The miracles of modern medical research and biotechnology offer hope for cures to afflictions as different and as devastating as cancer, AIDS and schizophrenia.

A national commitment to health promotion and disease prevention can bring the blessings of decent health to millions who would otherwise suffer from our neglect. But none of these opportunities can be realized without national leadership, public commitment, clear understanding and sound proposals.

The witnesses at today's hearing on national goals in health will include distinguished experts who will help diagnose the maladies and suggest solutions, and ordinary citizens who will bear witness to the personal suffering that could be avoided by wiser policy.

It is not enough to stand still, look back, sell the family jewels and hope for the best. Just as the darkness reminds us of the light, remembering things past is most useful when it reminds us of our ability to meet and master challenges.

In the end, the challenge is neither partisan nor new. Theodore Roosevelt called on America to "look up, not down; look out, not in; look forward not back; and lend a hand."

I hope that these hearings will remind us not just of where we stand, but of what we stand for. Full employment for our workers; compassion for our needy; first-class education for our children; quality health care and equal opportunity for all Americans, are not a dying dream. With better and wiser strategy, we can bring the real America closer to the great goals for which America has always stood.

[Applause.]

The CHAIRMAN. That is all right, Mrs. Dugan. It has been a little while since we have had that kind of outpouring here in these hearings, and we want everyone to get relaxed very early. I can see that that atmosphere has already permeated our hearings. [Laughter.]

We will just interrupt you for a moment while we thank you, in any event.

At this point we will receive for the record a statement by Senator Adams, who will be joining us later.

[The prepared statement of Senator Adams follows:]

STATEMENT OF HON. BROCK ADAMS, A U.S. SENATOR FROM THE
STATE OF WASHINGTON

Senator ADAMS. Mr. Chairman, let me begin by indicating how pleased I am to be a member of the Senate Committee on Labor and Human Resources. I commend the Chairman for the leadership he has demonstrated for many years on the vital issue of national health care; and I look forward to working with him as we seek to address the health care crisis facing us today.

Mr. Chairman, the combination of rising costs in health care and growing gaps in medical coverage in endangering our country's most precious resource—our own citizens. Too many of our people are hungry, too many are homeless, and now too few can pay the bill to be healthy. People delay necessary treatment because of cost concerns. Families are financially ruined by the costs of catastrophic illnesses. Public health hospitals serving the needy are starved for funds while private care providers close their doors to those unable to pay. While the President asks us to spend billions on defense, millions of Americans have no defense against the physical and financial problems that threaten them.

The Administration's response to this crisis is all too typical. It talks about numbers and efficiency and forgets about people. The President's recent budget message points out accurately that since 1960 the cost of health care in this country has risen three times faster than the rate of inflation. However, the Administration's proposals do not focus on ways to bring down these costs. Instead it again seeks to reduce the amount of assistance the government provides its citizens in obtaining medical services by slashing major medical funding below current service levels.

In the place of this necessary federal assistance, the Administration's wonder cure for our health care ills is capitation. The government now sets fixed reimbursement levels for medical services, and thereby supposedly halts increasing costs. The economic reality, however, is that whatever savings the Administration claims result from this scheme are short-term, because the major factors pressing costs upwards—technological advances, population growth, and rising labor and supply costs—are not being addressed. More importantly, the human reality is that hospitals must pay more attention to the financial needs of the system than to the medical needs of their patients, and people leave hospitals quicker and sicker.

Mr. Chairman, our national health care crisis will not be solved by making vital federal programs the villain. Instead we must focus on aggressive and imaginative uses of our existing programs to help control health care costs, and make more affordable health care a reality for every American citizen. I again commend the Chairman for his leadership in this area and I look forward to working with him.

Thank you.

The CHAIRMAN. Senator Hatch, as ranking minority member, I want to say what a pleasure it is to have the opportunity to refer to you as our "ranking minority member." [Laughter.]

I have enjoyed working with Senator Hatch, and I think there is no mystery of our occasional differences, but we have worked close-

ly together on many important matters affecting the domestic agenda for our country, and I have valued our cooperation in the past and look forward to the future.

I would be glad to recognize you, or let you yield to our colleague.

Senator HATCH. Thank you so much, Mr. Chairman.

Why don't I yield to Senator Thurmond?

The CHAIRMAN. We will yield to Senator Thurmond, with the understanding that the Senator from Utah's remarks will be printed in the appropriate place.

Senator HATCH. Well, I would like to make them, but I will wait until after Senator Pell. That will be fine.

The CHAIRMAN. Surely.

Senator THURMOND. Mr. Chairman, I want to congratulate you on becoming Chairman. You are succeeding a very able man in Senator Hatch, who has done a fine job. And I hope as much as possible we can make the work of this committee a bipartisan effort, as it is always very important.

You and I have been together on many committees. In fact, we serve as members of three major committees—Judiciary, Armed Services, and Labor and Human Resources—so we will see a lot of each other this year.

I want to take this opportunity to commend you on moving so quickly to conduct hearings on our National Health Goals. I look forward to working with you and other members of the Committee throughout the 100th Congress as we seek to address many of the issues raised here today.

I want to welcome the new members to this Committee. It will be a pleasure to work with all of the members. I especially wish to commend Senator Hatch for the fine job he has done, and I am sure that he will cooperate with you wherever it is appropriate.

Among these concerns, I understand we will receive testimony about the financial hardships a catastrophic illness can have on a family, the difficulties some face in obtaining health insurance, as well as current issues in the biomedical research and children's health fields. Furthermore, various legislative proposals will also be suggested.

This Committee will face significant challenges in addressing these issues. We will be seeking to craft legislation in the context of a \$2.16 trillion public debt, the interest payment on which is now equivalent to Federal income taxes paid by all persons living west of the Mississippi River. Those taxes do not pay for defense, health research or education; just interest on the Federal debt.

Moreover, the States too are operating under fiscal strain. We must be sensitive about disrupting local legislative agendas by imposing Federal mandates from Washington. As legislation is drafted, I will be particularly interested in how these two policies are considered.

In conclusion, our national health policy presents significant challenges, but I look forward to working with the members of this Committee in addressing the health needs of all Americans.

While my schedule may not permit me to stay for the entire hearing each day, I look forward to reviewing the testimony at a later time and will be briefed upon it. Again, I wish to thank you,

Mr. Chairman and Senator Hatch, for recognizing me out-of-order, so I can return to the Armed Services Committee, where Secretary Weinberger is outlining global challenges facing the defense policy of this Nation.

Thank you very much.

The CHAIRMAN. Thank you very much, Senator Thurmond.

I will call now on the Chairman of our Education Subcommittee, Senator Pell, who has done such important work in strengthening our education system.

Senator Pell?

Senator PELL. I have little to add, except to congratulate the Senator from Massachusetts on becoming Chairman. I enjoyed working under the Senator from Utah when he was Chairman, and I look forward even more to working with Senator Kennedy.

I would add also that I must apologize for not being at many of these hearings, because I am chairing the Foreign Relations Committee just down the hall.

The CHAIRMAN. We have heard of that Committee. [Laughter.]

Senator PELL. Unfortunately when you even have the national goals hearing on education, we already have hearings planned in the Foreign Relations Committee. So I will be popping in and out, but following your hearings as closely as I can. I commend you for the general thrust because I, too, have been very startled by these statistics, statistics that show that when it comes to the bottom line of health care—which to my mind is how long you live—that we come out very poorly. My recollection is we rank about eleventh, in the world. And yet, when it comes to what we spend on health care, we spend, I believe, more per capita than any other nation. We spend a higher percentage of our gross national product on health care than any other nation. Yet when it comes to that bottom line, longevity, we do not come out so well.

The interesting thing here is that the British spend about half of what we do, and their life expectancy at birth is almost equal to ours. I think these statistics that are very worrying, and I look forward to seeing solutions developed under the able chairmanship of the Senator from Massachusetts.

The CHAIRMAN. We thank the Senator from Rhode Island. We will be having that National Goal Hearing on Education on Wednesday. We understand his obligations, and we hope he will have an opportunity to spend what time he can with us. But we will look forward to working very closely from the lessons we learn on Wednesday and at our other hearings and other information to ensure both the consideration of the Elementary and Secondary Education Act and other legislative proposals.

The Senator from Utah is recognized.

Senator HATCH. Thank you, Mr. Chairman.

Before I start, I want to congratulate the new Chairman on initiating Committee hearings so quickly in this Congress. I think it is to his credit, and I want to congratulate you on your new chairmanship. I look forward to working with you in the same spirit of cooperation and assistance that you, I think, repeatedly showed during what I consider to be an unfortunately brief tenure in the minority. [Laughter.]

I want to publicly thank you, Ted, Mr. Chairman, for the courtesy that you and your staff have shown to me and my staff and other Republican members while transferring us from majority to minority status. I think you have been particularly gracious, and we appreciate that very much.

Over the last few years, we on this Committee have had the privilege of shaping the direction of and witnessing tremendous progress in our nation's health care system. We have seen little babies who were brought back from the brink of death by a modern miracle, liver transplant surgery, which could not have been done just a few years before. We have heard how costly and literally heart-stopping open heart surgery is being avoided through angioplastic techniques. We saw how computer technology and new, light-weight materials developed in the Space Program are being used to help severely handicapped individuals be more productive members of society.

In fact, these advances have not happened by accident. The Reagan Administration has invested \$28 billion in biomedical research over the last six years, and will spend another \$6.6 billion this year.

Now, I might note that in 1979 we only spent \$3.4 billion in this country on biomedical research.

Biomedical research has also been furthered by this Committee's efforts last year to pass the first major revision in 40 years to the authorization of the National Institutes of Health. Those efforts resulted in the addition of a new Arthritis Institute and the new Nursing Center to the Institutes already at NIH.

In addition, this Committee was responsible for legislation that has induced the private sector to expand its research efforts by rewarding research on orphan drugs and expanding patient protection for new drugs. Through our Patent Term ANDA² Bill and our Drug Price Competition Patent Term Restoration Bill, consumers have been saved well over a billion dollars thus far, as I understand it.

None of these things could have happened without bipartisan effort, and I personally want to thank Senator Kennedy and his Democratic colleagues for working with us over the last six years and helping us to do some of these things. We intend to cooperate and try and help as we continue to solve these problems involving medicine and health throughout our society.

Now, these medical advances are not cheap. Americans spent \$460 billion last year on health care; \$106 billion through the Medicare and Medicaid projects alone. In addition, business paid for 85 percent of the private insurance for our citizens in this society, but because of increased competition in the health care system over the last six years, assisted by legislation in this Committee that I have mentioned, to promote generic drugs, we continue to move closer than ever before to our goal of quality, affordable health care for all Americans.

A second positive trend that we have witnessed is an increased awareness on the part of Americans of what they can do to improve their own health. Americans are smoking less, drinking less, exercising more, and improving their dietary habits. Even businesses are now offering health promotion programs in the workplace.

Now, this partnership between business and our citizens and their government, it seems to me, has paid off handsomely. Today life expectancy in this country is at an all-time high, and infant mortality is at an all-time low, falling almost 20 percent during the last six years. And while the infant mortality rate for blacks is still disturbingly high, from 1980 to 1983, it improved almost twice as fast for blacks as it did for whites.

It is clear that the status of our nation's health care system is good and improving, but it is by no means perfect. There are still problems.

For example, we have remained myopically focused on hospital-based care. We need to give more attention to outpatient care, intermediate care facilities, and most importantly, to something that I have fought for every since I have been here, home health care.

There are Americans who may not receive adequate health care services. It has been estimated that up to 35 million people are either uninsured or underinsured. Hospitals and health care providers throughout the country maintain that, "uncompensated care", for these individuals, poses severe financial burdens for them.

We all can agree on the goal of providing affordable, quality health care for all Americans. That is the easy part. The hard part is to agree on the best method for achieving this worthwhile objective.

President Reagan took an important step in his 1986 State of the Union Address when he called on HHS Secretary Bowen, "to report by the end of the year on how the private sector and government can work together to address the problem of affordable insurance for catastrophic illness".

Now, the President's directive and Secretary Bowen's report set the wheels in motion, and I think they both should be commended for that. Now solutions are being debated and ideas being generated that involve new ways to tap the full promise of our nation's health care system.

Fortunately, we may be able to agree on some general principles. Last week the Chairman, Senator Kennedy, was quoted as saying, quote, "New approaches can work without increased spending." He went on to say, "I recognize the restrictions of the present budget, and I welcome the challenge to do more within those constraints."

Ted, when I read that, I thought you might have accidentally been quoting one of my speeches.

But I also agreed with comments by our distinguished first witness after our first panel, Mr. Califano. In an article describing the Chrysler Corporation's attempt to cut health care costs, he wrote the following:

For most of the 40 years since World War II, government, corporate management and unions have concentrated on providing more health care benefits for our people without realizing they were becoming hostages to costs beyond their control. Almost everyone assumed that more was better without ever assessing the correlation between higher costs and better quality care.

And while we are focusing on points of agreement, I must admit that I, too, believe that the Federal government must provide part of the solution to these problems. But unlike others, I also believe that some of our Federal policies are part of the problem. Instead

of simply spending more Federal money, placing bigger burdens on corporate America, small businessmen and women, and interfering with State governments who are attempting to meet the needs of their citizens, I hope we will work together to maximize the availability of quality health care at an affordable cost, thereby tapping the full potential of our private health care system.

Once again I want to congratulate you and your colleagues. We look forward to working with you during these coming two years. I have enjoyed working with you in the past six, and I appreciate all you have done.

The Chairman. Senator Simon?

Senator SIMON. Thank you, Mr. Chairman.

First, I want to join those who are congratulating you. I notice a little more enthusiasm on the part of some of us who are congratulating you and others.

I want to commend Senator Hatch, also, for it has been a cooperative effort for the last two years, at least that I have been in the Senate, and I am sure it will continue to be.

We have problems in this area. All kinds of illustrations, I see. I get a Christmas card from a woman whose handwriting suggests to me that she is probably up in years, but she had this simple message: "I have had flu for one month, but I cannot afford medicine to stop it." Somehow in this country, that should not be.

I think of a postal clerk in my State with a \$151,000 hospital medical bill.

I think of a man in my State whose income was substantially above average income, an executive in my State, who retired, bought a home in Hawaii. He talked to me on the phone maybe four to six weeks ago. His wife has had a problem with fluid on the brain. He now faces the loss of his home, the loss of everything. The costs are far above anything covered by insurance.

And it is not only these personal anecdotes; it is 38 million Americans who do not have any kind of health coverage.

I think clearly we can do much better. I want to commend Dr. Bowen, the new HHS Secretary, for particularly his work in long-term care. I think that is a direction we have to be moving in. But I would add that in the budget to cut back on NIH grants for research from 6,400 to 5,700, I do not think is a direction this country ought to be going.

Finally, Mr. Chairman, you used one word that I think we ought to be using more around here, and that is the word "dream". We cannot be satisfied with the status quo. We ought to be dreaming about the kind of America we want to build. And that America that we want to build ought to offer an opportunity for every American to have adequate health care and not to be fearing what might happen if something happens. We can remove that fear, and we ought to.

The CHAIRMAN. Thank you very much, Senator Simon.

Senator Humphrey.

Senator HUMPHREY. I will pass, Mr. Chairman.

The CHAIRMAN. We will move to our first series of witnesses this morning.

Senator HATCH. Mr. Chairman, if I could interrupt for one second, I have to leave in just a little while, and I would like to submit questions for the record if it would be all right with you.

The CHAIRMAN. Yes.

Senator HATCH. Thank you.

[Additional questions submitted by Senator Hatch, with accompanying responses, follow:]

QUESTIONS FOR MR. CALIFANO
FROM SENATOR ORRIN G. HATCH

1) I recently read your speech: "Who Lives? Who Dies? Who Pays? -- America's Health Care Revolution" about the steps Chrysler has taken to reduce health care costs. I was very impressed and I would like to ask you a few questions.

I was particularly impressed with your commitment to prevention. It does make more sense to prevent medical problems than to palliate them after they have occurred. Because of this, I authored legislation to increase our education efforts about the health risks of cigarettes, smokeless tobacco, alcohol, and other drugs. Furthermore I have supported extensive legislative initiatives to promote healthy lifestyles and increase prevention research.

As I understand it, Chrysler has gone a step beyond education efforts and is using financial incentives to encourage employees to live healthier lives. The state of Utah has also adopted these initiatives for state employees. I was wondering how practical it is for the federal government to adopt financial incentives and if it is technically feasible, how politically feasible is it?

2) I have always been a strong advocate of increased competition in the health care system. I was pleased to sponsor the law to increase the availability of generic drug in an attempt to increase competition and hold down costs and I have supported other legislation to increase competition in the health care system.

You note in your testimony that within 10 years we will need only half the hospital beds we have today. You also noted that hospitals had been experiencing record profits and that the rate of increase in health care costs has started to slow.

But there are several areas where competition has had a detrimental effect. One of these is rural health care. Small rural hospitals don't have the economies of scale that larger ones do. Most of the hospitals which are losing money and many of the hospitals which are considering closing are small rural ones. If a hospital in New York City or Boston or Los Angeles closes, patients in those cities usually have several other hospitals from which to choose. But if a hospital in rural Utah or rural Iowa or rural Montana closes, patients may have to drive for one to two hours to reach the next nearest hospital.

Do you have any ideas on how we can maintain quality medical care in rural settings?

3) I was pleased to read that you think one of our major priorities should be overhauling our medical malpractice system. Last year I introduced legislation to encourage capping awards for pain and suffering, limiting attorneys fees, and increasing state licensing review activities. Some members of this committee have questioned that need.

Do you still feel that overhauling the medical malpractice system is a major priority and what do you feel should be done?

4) You have talked a lot about how less medical care is better. Is there evidence that doing fewer coronary bypass operations or fewer hysterectomy's or fewer laminectomy's is actually better health care or are we just saving money?

5) During the last Congress, there were several legislative proposals to mandate state run health insurance risk pools for the uninsurable. While I agree that the creation of state run risk pools may be a good suggestion, how do you feel about proposals to require that large employers pay for any deficit created by such a pool? Or health care benefits be taxed in order to subsidize state risks pools?

6) You pointed out that life expectancy at birth in Singapore is the same as in our country. Do you have an explanation for that? Are we not spending enough for health care or are we smoking, eating, and drinking to much?

7) You pointed out that employees in lower paying jobs are the ones most likely to be without health insurance and suggested that mandatory minimum health insurance coverage would solve that problem. It seems to me that before Senator Kennedy and I endorse that proposal we had better know how many of those low income employees will end up still without health insurance because they lost their job.

If all we end up accomplishing is taking jobs away from Americans, thats not a very impressive accomplishment. Can you tell us how many people will lose their jobs if we adopt your suggestion?

Responses by Joseph A. Califano, Jr.
To Additional Questions from Senator Orrin G. Hatch

Testimony of January 12, 1987 before the
Committee on Labor and Human Resources

1. It is certainly possible for the Federal government to adopt incentives for its employees to live healthier lives. At Chrysler, employees who are non-smokers can buy additional life insurance at lower rates than smokers. The company will also pay the cost of a health risk appraisal and 50 percent of the cost of a health education course recommended by a risk assessment -- smoking cessation, for example. There is no reason why the Federal government could not do the same for its employees.

It terms of the Federal medical insurance programs, it would be a great step forward simply to expand Medicare coverage to pay for an annual physical examination and risk assessment. This would encourage Medicare beneficiaries to understand their health status and to adopt healthier lifestyles and would reimburse doctors for their time.

While such an expansion would mean an increase in Medicare spending in the initial years, it should save money in the long run from early detection of disease and from improving health habits.

2. The most important step we can take to support rural health care services is to assure that people living in rural areas have at least a minimum package of health insurance benefits. We know that health care services follow reimbursement and if more people in rural areas had

insurance coverage there is no doubt that rural hospitals would be in better shape financially. Any business subject to minimum wage requirements should be required to provide a minimum level of health care benefits. The self-employed, like family farmers, should be able to deduct the entire cost of health insurance premiums for themselves and their families.

3. I continue to believe that major changes are needed in our medical malpractice system.

To achieve fundamental reform, states must get medical malpractice out of the courtroom and into the administrative law arena, with limits on the amount of recovery. Such limits would provide modest payment for pain and suffering, and link recovery largely to costs of health care, rehabilitation and disability and to replacing reasonable loss of income due to inability to work. In cases of wrongful death caused by malpractice, recovery would be limited largely to the reasonable loss of income to the surviving spouse or children.

There are ample analogies in workers' compensation and arbitration procedures that can be adapted to this crisis. Contingent legal fees should also be reduced.

In 1985, the United States Supreme Court let stand a California court decision upholding a state law with a \$250,000 limit on non-economic malpractice awards and a sharply reduced scale for contingent legal fees.

Malpractice itself needs to be redefined. Doctors should be held to reasonable standards of care. States should set standards that are reasonable locally, to the hospital, doctor or clinic where the patient goes, and not impose impossible-dream standards on every doctor and hospital in America. The tests doctors truly need to diagnose and treat their patients should be sufficient for their lawyers to prevail in the courtroom.

The skyrocketing costs of malpractice insurance are due in part to the inability of the medical profession and government watchdogs to keep incompetent physicians out of the clinic and the operating room. For doctors, reform of malpractice laws begins at home, with reform of their own medical discipline systems.

Professional medical disciplinary systems are too often not doing their job. In 1984 state medical boards in Nevada, Utah, Oregon, and Mississippi each disciplined more than one physician out of every hundred. But boards in New York, Massachusetts, Nebraska, Hawaii, and the District of Columbia disciplined less than one per thousand. Delaware and Alaska took no actions at all.

The states must put in place timely and tough license revocation procedures and effective methods to identify and weed out physicians and other providers who pose a threat to the public.

4. Every operation, every stay in the hospital carries with it its own risk. In coronary artery bypass

surgery, for instance, a patient runs a 2 percent risk of dying on the operating table, a 5 percent risk of a heart attack during surgery and a 10 percent chance of a serious complication like stroke, weakening of the heart muscle, or infection.

The evidence available suggests that 20 to 25 percent of hospital admissions are inappropriate. Studies of variations in the rates of surgery in different geographic areas have found no relationship between the number of surgical procedures performed and the health status of the population. Even if eliminating unnecessary medical care saved no money, it would be worth doing to simply avoid the deaths, infections and other complications that occur as the unintended result of surgery and hospital stays.

5. I believe that this is a matter for each state to decide. In general, support for state risk pools should be as broad as possible. Any deficits should be made up out of general revenues, if possible. I would turn to a tax on health insurance premiums or daily hospital charges only as a last resort.

6. There are three basic reasons: First, we don't take care of ourselves. Second, we spend too much money on expensive, high-tech medical care and not enough on educating people on how to live healthy lives. Third, we don't spend enough money on basic medical services for those who need them. This country's alarming infant mortality rate -- a large factor in life expectancy -- is due in part to our

failure to assure access to prenatal care. Almost one-quarter of all American mothers -- and 40 percent of Black mothers -- do not receive early prenatal care,

7. I do not know whether any workers would lose their jobs as a result of requiring employers to provide a minimum level of health insurance. Two things can be done to lessen the financial impact on employers, however. One is to develop ways to pool the employee populations of small business so that they can buy insurance at the same rates large employers do. Currently, small businesses face as much as 40 percent higher premiums. Another way to reduce the impact is to phase in the requirement over several years, increasing the number of employees covered and the amount of employer contributions gradually.

The CHAIRMAN. Before introducing our first panel this morning, I want to comment as a matter of business on the way this Committee intends to proceed. With certain exceptions—particularly those who have not perhaps had the opportunity to appear before our Committee, our guests from our 50 States who come here to tell us about some of their very special concerns and needs and how it has a national application, and a few others—we are going to insist that those who come before our Committee file their full statements and to make an oral presentation in the given time.

Having been here now 24 years, I think all of us spend too much time listening to people read statements. And if there are some special recommendations that deserve some special consideration, obviously, we will be flexible on that rule. But I would hope that any of those who appear before our Committee over the period of time I am Chairman will file their statements and present their opening statements briefly and concisely.

Senator PELL. Excuse me—and would file them 24 hours ahead.

The CHAIRMAN. File them 24 hours ahead, yes, I am glad to be corrected. And I want to commend those who are testifying today; they did do that—some, even further ahead—and it made it very, very valuable weekend reading. There are a number of witnesses, and I see them all out there, and I want to get to them, but I think without exception—without exception—they provided that, or an outline, and it was very, very valuable in preparation for the hearing.

Now, to introduce our witnesses, I would hope that those on the Committee and in the Senate will realize that this Committee is about statistics and about flow lines and charts and trends, but it is mostly about people. It is about Americans who have special needs and who believe that we have at least some opportunity to provide some relief. We have no magic wands. We are aware of the limitations by which we are restricted in terms of financial resources and others, but there are things that can be done and that should be done, and we are strongly committed to assuring that everything that can be and should be done will be done.

This Committee is about people, and that is going to be something that hopefully will never be lost, at least over the time that I have the good fortune and opportunity and very deep privilege to be able to chair this Committee.

Our first panel will be some very good people who have been facing the health care challenge in our country over the recent and past year and who have some special messages.

Let me say at the outset that all of us are familiar with the slogan that, well, you can find families like this anywhere in America, and it really is not illustrative of the problem. My friends, we could find more of these kinds of witnesses today than we could find a few years ago, and they are illustrative of the problem in a very real way.

So let us hear our witnesses. Our first panel this morning includes Mr. and Mrs. John Muir, from Hyattsville, Maryland, and we will welcome the opportunity to hear from them.

I would hope all of our witnesses will feel relaxed and tell us their stories. I will ask you some questions. We will follow the ten-minute rule, but I will take initially what time is necessary just to

pose the questions in order to be able to make the record, and then we will alternate back and forth for the various members of the Committee.

Mr. and Mrs. Muir, we are glad to have you here. Maybe it would be best if I just asked you some questions, if that would be all right, just to try and tell the story.

STATEMENT OF MR. AND MRS. JOHN MUIR, HYATTSVILLE, MD; HELEN GREEN, MEMPHIS, TN; CONNIE GATES, JOHNSTOWN, PA; AND RUTH DUGAN, INDIANA, PA

The CHAIRMAN. Maybe you would each indicate how old you are—Mrs. Muir?

Mrs. MUIR. Twenty-one.

Mr. MUIR. I am 28.

The CHAIRMAN. Maybe you could tell us whether you were employed and approximately what each of you were making.

Mrs. MUIR. I was working for the State Employees' Credit Union, making about \$13,000 a year.

The CHAIRMAN. Mr. Muir?

Mr. MUIR. I work as an electrician for T&H Electric, and I make about \$24,900 a year.

The CHAIRMAN. About \$24,000 a year, and Mrs. Muir makes about \$13,000. And this was the State of Maryland Credit Union where you were employed, Mrs. Muir, is that right?

Mrs. MUIR. Yes.

The CHAIRMAN. And you had health insurance at that job, did you?

Mrs. MUIR. Yes, I did.

The CHAIRMAN. And did you leave that job after you became pregnant with your first child?

Mrs. MUIR. No; I had to take a leave of absence, and at that time, they could not hold my position, so I had to quit.

The CHAIRMAN. So you did take a leave of absence after you became pregnant?

Mrs. MUIR. Yes, I did.

The CHAIRMAN. And when was the baby due?

Mrs. MUIR. July 23, 1986.

The CHAIRMAN. And you took a leave of absence at what month, do you remember—several months before that?

Mrs. MUIR. Yes. I had to take one in April.

The CHAIRMAN. In April, okay. And you were hospitalized in March, though, of last year, during the pregnancy, weren't you?

Mrs. MUIR. Right.

The CHAIRMAN. And could you tell us about that?

Mrs. MUIR. I had to go in for—I was getting ready to miscarry, and we tried to elevate the baby. I had to lay elevated for 12 days to try to hold him in, and I had to take my leave. That was my pregnancy leave there, and then at that time, I had to take off.

The CHAIRMAN. And you were in the hospital how long?

Mrs. MUIR. Ten days.

The CHAIRMAN. And did you have health insurance from your prior employment to cover that hospital bill?

Mrs. MUIR. Yes, I did.

The CHAIRMAN. And what happened when you went home from the hospital?

Mrs. MUIR. Well, I stayed elevated on the couch for two days, and one night, the baby just came out, and we went to the hospital at that time.

The CHAIRMAN. All right. So the baby was born prematurely, is that right?

Mrs. MUIR. Yes.

The CHAIRMAN. And during the time of the birth, I understand—could you just relate some of the circumstances at that time? Didn't you call the ambulance, and then you gave birth—maybe you could tell us the story just briefly.

Mrs. MUIR. Well, we called the doctor. We had to call his emergency number.

The CHAIRMAN. This was at the time of the birth?

Mrs. MUIR. Right. I was getting ready to have the baby. And we waited for him to call back, and he called back and told us to hurry up and get to the hospital.

By the time I got up from the couch, it was getting to be too late, so I ran to the bathroom. And we called the doctor again and told him that we did not have enough time to get to the hospital. And we were waiting for his call to come back, to tell him this, and it was taking a long period of time, so we called the hospital and had an ambulance come to get us.

At that time, as soon as we hung up, the phone rang, and I had the baby in my bathroom.

The ambulance still was not there yet, so we grabbed a beach towel, ran and wrapped the baby up, drove around the block, and I saw the lights flashing off of a van, and we could tell that the ambulance was up at the house. So we drove around the corner, and as we were driving, the car stalled. The ambulance was getting ready to pull off, so we ran and we tracked down the ambulance, and they took us to the hospital from there.

The CHAIRMAN. You were running after the ambulance at this point?

Mrs. MUIR. Yes.

The CHAIRMAN. The baby was not due until July, but was born in April, is that correct?

Mrs. MUIR. Right.

The CHAIRMAN. And how much did it weigh at birth?

Mrs. MUIR. One pound, five ounces, and it went down to one pound, two ounces.

The CHAIRMAN. And how long was the baby in the hospital?

Mrs. MUIR. For five months.

The CHAIRMAN. And how much did the bills amount to?

Mrs. MUIR. Well, the hospital bill was about \$469,000.

The CHAIRMAN. It was how much?

Mrs. MUIR. Four hundred sixty-nine thousand.

The CHAIRMAN. Four hundred sixty-nine thousand dollars.

Mrs. MUIR. We also had private doctors coming in and out, which included about \$100,000.

The CHAIRMAN. Doctors about \$100,000. And did your health insurance cover any of those expenses?

Mrs. MUIR. No, it did not.

The CHAIRMAN. Why not?

Mrs. MUIR. They said he was not on my policy when he was born.

The CHAIRMAN. What did they mean he was not on your policy?

Mrs. MUIR. I had a single coverage for myself only, so they said they could not cover anything due to the baby; they could only cover me. So they covered the hospital bills for me being in the hospital for the ten days, and then I went back in for two more days. That is all they covered.

The CHAIRMAN. So it covered you, but evidently they draw a distinction between you and you giving birth to the baby.

Mrs. MUIR. Right.

The CHAIRMAN. Mr. Muir, you had health coverage with the Electrical Workers Health and Welfare Fund, is that right?

Mr. MUIR. Yes, sir.

The CHAIRMAN. And how much did that cover?

Mr. MUIR. The limit was \$100,000—

The CHAIRMAN. That is the limit on the top, is that right?

Mr. MUIR. Yes, the top that we were covered for. And they went ahead and paid \$110,000, \$10,000 above what they should have paid, which was good of the Union to do that. And after that, that was it.

The CHAIRMAN. And how much do you still owe?

Mr. MUIR. It is about \$369,000, plus \$60,000 for private doctors.

The CHAIRMAN. Has the hospital made any efforts to collect the money you owe?

Mr. MUIR. Yes. They had a collection agency call us up, "Where is our \$360,000?" And I said, "Well, it is in my Swiss account. Let me fly over and get it."

The CHAIRMAN. Except you did not have a Swiss bank account?

Mr. MUIR. No, I did not. [Laughter.]

It was either that or rob a bank, and I was not going to do that.

The CHAIRMAN. Have you been trying to get Medicaid coverage?

Mr. MUIR. Yes, we have.

The CHAIRMAN. What is the status of that effort?

Mr. MUIR. I have heard nothing. They keep going, like, they need my birth certificate now, and then it is just one thing after another. They will not come out all at once and tell us what we need. They have been dragging it on all summer long, and the child is almost a year old now, and nothing has been done yet.

The CHAIRMAN. It will be difficult—you have automobiles, obviously, and you need those to go and work, don't you?

Mr. MUIR. That is right.

The CHAIRMAN. If you do not have those, it will be very difficult to get to your work, where you are still working.

Mr. MUIR. Right.

The CHAIRMAN. Mrs. Muir, did you go to work last fall, part-time, to help with the expenses?

Mrs. MUIR. Yes, I did. I went back after my pregnancy leave, before the baby came home; I had to go back to work for a little while.

The CHAIRMAN. And how many jobs did you have?

Mrs. MUIR. Well, I started out with two, and when I found out I was pregnant, I quit my part-time job to stick with my full-time.

The CHAIRMAN. So you had two jobs, and Mr. Muir has one.

Mrs. MUIR. Yes.

The CHAIRMAN. And then you halted at the time you were pregnant; is that right?

Mrs. MUIR. Right; I quit the part-time job.

The CHAIRMAN. How is the baby doing now?

Mrs. MUIR. He is doing real good, eleven pounds, four ounces.

The CHAIRMAN. What do you think all this says about the availability of proper and affordable health care for American citizens such as yourselves?

Mrs. MUIR. I think it could have been a little bit better. I think they should have started us out in the very beginning when the child was in the hospital. We could have had all this paperwork done and settled by now. Instead, we are still waiting, we are still getting phone calls, and this stuff could have all been settled a long time ago while he was in the hospital.

The CHAIRMAN. Well, when a young American family with the equivalent of about \$36,000 in terms of income between the two of you, and each of you has scattered kinds of coverage, and still it does not cover what is certainly one of the most basic and fundamental acts of creation—of giving birth—and leaves you with a \$460,000 deficit of which the collecting agency is, as I understand, threatening you about your home, your house and other kinds of threats, we have to really ask ourselves now whether we as a just and humane society are really meeting our responsibilities to hard-working people whose only desire is to work and to provide for their families.

What are you going to try and do? Are you going to try and chip away at this?

Mrs. MUIR. We are going to wait. We are going to wait for the State Medicaid to see what they cover. We do not want to gyp the hospital out of anything. They did a very good job. And we could have filed bankruptcy the way they were pressuring us, but we did not. We waited, and we are going to hold out and give the State Medicaid a chance to give the hospital their money, and whatever they do not pay, we cannot help them with, because I was off from work for four months. And we wrote them a letter and we told them, if you do not help us get the State Medicaid, we will not be able to pay anything on it. So we are just waiting now.

The CHAIRMAN. Okay. I notice Senator Adams here. We welcome Brock Adams, a new member of the Committee with a distinguished record in the Congress. We are glad to have him back in the Committee.

Senator ADAMS. Thank you, Mr. Chairman.

The CHAIRMAN. What I intend to do is inquire of each of the witnesses, and then proceed with questions for each of them, if that is all right.

Senator ADAMS. Fine.

The CHAIRMAN. Mrs. Helen Green. Mrs. Green, we are glad to have you here this morning, and we look forward to your testimony.

Would you be kind enough to tell us how old you and your husband are?

Mrs. GREEN. I am 68, and my husband is 72.

The CHAIRMAN. And where do you live?

Mrs. GREEN. Memphis, Tennessee.

The CHAIRMAN. You are both retired, are you?

Mrs. GREEN. Yes.

The CHAIRMAN. And what occupations did you and your husband have before you retired?

Mrs. GREEN. Well, I was a corsetiere in a big department store of M.M. Kohn's, and my husband was in a service station.

The CHAIRMAN. And do you have children?

Mrs. GREEN. Yes, sir, but they are in different parts of the United States.

The CHAIRMAN. How many do you have?

Mrs. GREEN. I have one son, and my husband has a daughter.

The CHAIRMAN. And do you both receive Social Security?

Mrs. GREEN. Yes, sir.

The CHAIRMAN. How much does that amount to a month?

Mrs. GREEN. I get \$240, and my husband gets \$419.

The CHAIRMAN. And is that your total income?

Mrs. GREEN. That is it.

The CHAIRMAN. Do you own your own home?

Mrs. GREEN. Yes, sir.

The CHAIRMAN. And I understand your husband was hospitalized in 1982. Could you tell us about that?

Mrs. GREEN. Yes, sir. Well, he went in—he did not think the problem was what it was, but it turned out he had a ten-pound, four-ounce tumor on his right kidney, and they had to remove that; and he had a hernia in his front, the navel, and they had to take that out. He was in the operating room about six hours, and they tell us that he really turned blue on them three times, and they thought he was going to die then, but God saved him.

The CHAIRMAN. How long was he in the hospital?

Mrs. GREEN. Sixteen days.

The CHAIRMAN. And I understand that at that time he was covered by Medicare.

Mrs. GREEN. Yes, sir, he was all right. His hospital bill and everything was fine. We finally got everything but one doctor paid, and the anesthesiologist.

The CHAIRMAN. So you got the hospital bill paid, as I understand it. You have two health insurance policies, too, don't you?

Mrs. GREEN. Yes, sir, we did.

The CHAIRMAN. You did. But you did not get the doctor's bills; is that correct?

Mrs. GREEN. That is right.

The CHAIRMAN. You did not get the surgeon's bill.

Mrs. GREEN. That is right.

The CHAIRMAN. How much was that; do you remember?

Mrs. GREEN. Well, I forget what Medicare paid for him, but we owed almost \$3,000 at the end.

The CHAIRMAN. Three thousand. And the anesthesiologist?

Mrs. GREEN. Well, our part was \$507.

The CHAIRMAN. And did the anesthesiologist turn his bill over to a collection agency?

Mrs. GREEN. Yes, sir.

The CHAIRMAN. Did the sheriff come out to your house with a warrant?

Mrs. GREEN. Yes, sir, he did.

The CHAIRMAN. What did he say to you?

Mrs. GREEN. He told us that he would just give us a slight warning that they could come in and take our refrigerator out of our home, or anything that they wanted, for that bill, or even go so far as to sell our home.

The CHAIRMAN. How long have you lived in that home?

Mrs. GREEN. Eight years.

The CHAIRMAN. Did you make arrangements to pay the anesthesiologist?

Mrs. GREEN. Yes, sir. We tried. We made arrangements, and we would have gotten that done, but I had to go in the hospital in 1983. I would have collected Medicare in 1985, November the 18th, my birthday, but the doctor would not let me wait any longer, I had lost so much blood. They made me go in in February, before I had Medicare.

The CHAIRMAN. But you had to drop these other health insurance policies, did you?

Mrs. GREEN. Union Fidelity, but we kept Physician Mutual.

The CHAIRMAN. Oh, you dropped one of them because you could not pay for it, is that correct?

Mrs. GREEN. That is right.

The CHAIRMAN. And as you mentioned, you put off going to the doctor until you would be eligible for Medicare, is that correct?

Mrs. GREEN. I tried, but it did not work.

The CHAIRMAN. What do you mean by that, you put it off—what was going through your mind when you were thinking about putting off trying to get some important care that you felt you needed, in order to wait for Medicare?

Mrs. GREEN. Well, we knew I did not have enough insurance to take care of me, but my doctor was wonderful. He put us through a program where we did not have to pay the doctor, so that while I was there, my doctor, the main doctor, could let the young doctors come in and talk with me and examine me like he did.

The CHAIRMAN. But what did you mean by you had to wait for Medicare?

Mrs. GREEN. I did not have adequate insurance.

The CHAIRMAN. And you knew when you got Medicare that you would get some—

Mrs. GREEN. It would be a lot of help, yes, sir.

The CHAIRMAN. So even though you knew you were ill, and you knew you were sick, you said that you were not going to go to the hospital, were not going to the doctor until you were going to be able to be relieved from these kinds of financial limitations, and in that way, endangering your health. Weren't you worried about it?

Mrs. GREEN. Surely.

The CHAIRMAN. Was your husband worried about it?

Mrs. GREEN. Crazy about it. But there was nothing we could do about it. We were already harassed enough, you know, just pressured, because of the other bill. And we did not have enough coming in to take care of it. And after my husband was released, he lost his job.

The CHAIRMAN. All right. Let me just take it one at a time. So then eventually you went into the hospital, and the doctor worked out so there would not be doctors bills; is that correct?

Mrs. GREEN. That is right.

The CHAIRMAN. And how long were you in the hospital?

Mrs. GREEN. Fourteen days.

The CHAIRMAN. And how much did you still owe the hospital when you left?

Mrs. GREEN. They charged me, I think, over \$1,000 for their part.

The CHAIRMAN. Okay. Now, did the hospital turn it over to a collection agency?

Mrs. GREEN. Yes, sir.

The CHAIRMAN. Did they make harassing phone calls to you?

Mrs. GREEN. Yes, sir.

The CHAIRMAN. What sort of things did they say?

Mrs. GREEN. Well, among the most heart-breaking thing is he kept telling me, "Well, I notice you have a telephone. If you have a telephone, you could put that money on us; you could be sending that to us to pay for that." And of course, you know, when you get our age and older, it is detrimental that you have a phone in your home—

The CHAIRMAN. It is essential.

Mrs. GREEN. Surely, it really is.

The CHAIRMAN. So were you worried about losing your home?

Mrs. GREEN. Yes, sir.

The CHAIRMAN. And did you decide to declare bankruptcy?

Mrs. GREEN. Yes, sir. We really had to.

The CHAIRMAN. And when your husband left the hospital, was he supposed to obtain some medicine to take?

Mrs. GREEN. Yes, sir. I think at that time it was about \$23 a month, and he said there was no way that he could have it refilled, because he could not get it done every month for the rest of his life. He would not even get the first one.

The CHAIRMAN. Has he ever taken it?

Mrs. GREEN. No, sir.

The CHAIRMAN. And why not?

Mrs. GREEN. We have no money for it.

The CHAIRMAN. And you were supposed to go back for checkups after your cancer operation, is that correct?

Mrs. GREEN. Yes.

The CHAIRMAN. How often were you supposed to go?

Mrs. GREEN. Every six months.

The CHAIRMAN. And have you gone?

Mrs. GREEN. Once.

The CHAIRMAN. Why haven't you gone regularly? You were told to go.

Mrs. GREEN. Well, the clinic that they sent me to charged \$9.50 for each visit, but if you go at the six-month time, though, they charge \$74. Well, the first time I would have gone in, I did not have the \$74 to have paid any more, because Medicare, you have to pay the first \$75 of every year, regardless. And when you are in a situation like we are, you do not have the \$75.

The CHAIRMAN. Are you having problems now?

Mrs. GREEN. Many, yes, sir. I need to go back into the hospital.

The CHAIRMAN. Don't you think you ought to go to a doctor?

Mrs. GREEN. Oh, I know if I go back, he will insist on putting me in the hospital.

The CHAIRMAN. How is your husband's health?

Mrs. GREEN. Not too good. He is having trouble with his hips and pains in his back, and he does not know whether it is his other kidney causing it, his only good one left, or if it is from his operation. But he will not even go and see a doctor, because he knows we will not be able to take care of it.

The CHAIRMAN. How long have you and your husband been working, just generally? When did you start working?

Mrs. GREEN. Oh, I have not worked too many years, but——

The CHAIRMAN. How about your husband?

Mrs. GREEN. Oh, he has worked hard all of his life.

The CHAIRMAN. He has worked all his life.

Mrs. GREEN. Oh, yes, just as hard as——

The CHAIRMAN. You have worked a good part of your life.

Mrs. GREEN. Yes, sir.

The CHAIRMAN. What is your own kind of reaction as hardworking people about the American dream when you find out that you are in this kind of circumstance and cannot afford even the most basic kind of health care? Are you distressed by this?

Mrs. GREEN. Awfully. When you have always lived a life that you could just go to the grocery store and buy anything that you wanted for a meal, and not think too much about it, and then all of a sudden, if you have got coffee and toast and preserves two or three times a day before you start your day, you are lucky.

The CHAIRMAN. Do you worry about this a good deal?

Mrs. GREEN. Yes, sir, we surely do.

The CHAIRMAN. And your husband as well.

Mrs. GREEN. Yes.

The CHAIRMAN. Mrs. Green, thank you very much. Mrs. Gates is from Johnstown, Pennsylvania. Maybe you could tell us how old you and your husband are.

Mrs. GATES. I am 33, and my husband is 36.

The CHAIRMAN. And where do you live?

Mrs. GATES. Johnstown.

The CHAIRMAN. And do you have some children?

Mrs. GATES. I have a son who is eight years old.

The CHAIRMAN. And I understand your husband was seriously injured a few years ago?

Mrs. GATES. In 1975.

The CHAIRMAN. And could you tell us what happened?

Mrs. GATES. He was a passenger in a coal truck. His truck had broken down, and he had his friend take him down to the generating station, where we live, and it went down over the Haws Pike. It travelled 200 feet down over the cliff to the railroad tracks. He was hospitalized 72 days the first time.

The CHAIRMAN. As I understand, he had multiple fractures of the pelvis, a fractured skull, fractured sternum, fractured left scapula, facial nerve pulls multiple abrasions and lacerations. It is amazing that he survived.

Mrs. GATES. Yes.

The CHAIRMAN. We are certainly, all of us, fortunate that he did. How long was he in the hospital?

Mrs. GATES. He was in the hospital the first time 72 days.

The CHAIRMAN. And did Workman's Compensation cover the hospitalization?

Mrs. GATES. Yes.

The CHAIRMAN. Is he permanently disabled?

Mrs. GATES. Yes.

The CHAIRMAN. And did he receive disability payments?

Mrs. GATES. Four hundred eighty-eight dollars a month.

The CHAIRMAN. And are you employed?

Mrs. GATES. Yes, I am.

The CHAIRMAN. Do you have health insurance in connection with your job?

Mrs. GATES. I have Blue Cross that just covers for us employees at work.

The CHAIRMAN. Just the employees at work?

Mrs. GATES. Yes, for myself.

The CHAIRMAN. It does not cover your husband?

Mrs. GATES. No. I carry a private policy on him that I have had since 1971.

The CHAIRMAN. And does it cover your son?

Mrs. GATES. Yes.

The CHAIRMAN. And what does your other policy cover?

Mrs. GATES. Since his accident, his medical health has not been good enough to get more coverage, so it only pays 40 to 60 percent.

The CHAIRMAN. And you have to pick up the rest?

Mrs. GATES. Yes.

The CHAIRMAN. Now, your husband was hospitalized again in 1984?

Mrs. GATES. Yes.

The CHAIRMAN. Could you tell us about that?

Mrs. GATES. He was hospitalized in 1984 for kidney stones, and while he was there, a nurse had dropped the IV on the floor, and she put it back into his vein. Two weeks later, he contracted an infection, which now he has ulcerative colitis, and he has been in bed since October.

The CHAIRMAN. Is it severe?

Mrs. GATES. Yes. He was in the hospital all last, past November. He has been in bed since. He came home Thanksgiving Day.

The CHAIRMAN. Has he lost a lot of weight?

Mrs. GATES. He lost 27 pounds in three weeks.

The CHAIRMAN. How much were the hospital and doctor bills for that?

Mrs. GATES. For November, they were about \$22,000.

The CHAIRMAN. Is that hospital and doctors?

Mrs. GATES. Some of the doctors' bills are not in yet.

The CHAIRMAN. How much do you still owe for all the hospital and doctor bills?

Mrs. GATES. I would say over the past two years, between \$30,000 and \$40,000.

The CHAIRMAN. Did the hospital suggest at one point that you might lose your home?

Mrs. GATES. They send me notices for sheriff sales.

The CHAIRMAN. For sheriff sales. What does that mean to you when you see a sheriff sale? It means they could auction off your home?

Mrs. GATES. Yes.

The CHAIRMAN. Does your husband require medication?

Mrs. GATES. Last year he had an infection on top of the ulcerative colitis. It was \$100 a dose, and he had to have two doses a day for ten days. And his doctor had called the Cancer Society and medical assistance and Operation Touch in Johnstown, and he could not get any help. And he called Minneapolis—he knew a pharmacist out there that flew the medication in to the county airport for us.

The CHAIRMAN. Have you attempted to obtain Medicaid?

Mrs. GATES. They told me I was not eligible because of my wages.

The CHAIRMAN. Because of your wages. What are you earning now?

Mrs. GATES. I am an office clerk at Troy Laundry, and I make \$9,800 a year.

The CHAIRMAN. That is still below poverty for a family of four, and just about it in terms of a family of three.

You have a 1972 car.

Mrs. GATES. Yes.

The CHAIRMAN. What does that mean to you?

Mrs. GATES. From my husband's home life, they never had much, and that was the first thing we bought when we were married. The car has 19,000 miles on it and has classic plates. And because I have a classic car, they want me to sell it and my property and any available jewelry I have to pay this hospital bill. And I have until the end of the month to decide what I am doing.

The CHAIRMAN. So this is something that has been in the family, and I understand you want to be able to give it to your son as something that you have held onto and has meant something special to both of you.

Mrs. GATES. Yes.

The CHAIRMAN. And because you have that is one of the reasons, I suppose, as well as the wages, why you are denied Medicaid eligibility.

Mrs. GATES. Yes.

The CHAIRMAN. In caring for your husband, as I understand, you have to carry him upstairs every time?

Mrs. GATES. Yes, I do.

The CHAIRMAN. You yourself have to carry him?

Mrs. GATES. I put him on my back, and I crawl up the steps four times a day.

The CHAIRMAN. Now, in addition to these problems, I understand that your eight-year-old boy had surgery last week; is that right?

Mrs. GATES. He had surgery Thursday morning.

The CHAIRMAN. Is he covered by your health insurance?

Mrs. GATES. No. I did not have good hospitalization, so they sent him home Saturday.

The CHAIRMAN. We can slow down. Mrs. Dugan, would you get Mrs. Gates some water?

Okay. So he is not covered. And as I understand, you took out a small policy to cover him in school; is that right?

Mrs. GATES. No. He was on the Childcaring Program, that new Blue Cross program that the State came out with, but it does not cover for surgery; it is just strictly outpatient. And they called me down to the credit office at the hospital Friday evening because it was not going to be paid for, and he was discharged Saturday.

The CHAIRMAN. So that is on top of the other bills.

As hardworking people—you have been working all of your life, and as I understand, your husband has—you have gotten some coverage in terms of workmen's compensation, taken out insurance programs to cover yourselves, special programs to cover your son, and they just do not seem to make it. What does that say to you about the health care system?

Mrs. GATES. It is not fair.

The CHAIRMAN. It is not fair. Probably no one could say it any better, or certainly with more authority.

Mrs. Dugan, we are glad to have you here. Tell us where you live and how old you and your husband are.

Mrs. DUGAN. I live in Indiana, Pennsylvania. I am 28 years old; my husband is 33. We have two children, a six year-old boy and a two year-old son.

The CHAIRMAN. Your husband formerly worked at a rubber company in your home town, is that right?

Mrs. DUGAN. That is correct; McCrerie Tire and Rubber. He was locked out of his job on March the 2nd. It was a lock-out. It is not a strike. The men were still wanting negotiations to go on and stay inside of the plant and work, but the company had gone behind our backs two months prior to that and interviewed other men. It was a set-up. And when that date came, they locked our men out.

The CHAIRMAN. And did he lose his insurance then, too?

Mrs. DUGAN. We thought he lost his insurance, but I had a question regarding some of my prescription bills, and I called the company, and they said, "Oh, it was good for 30 days after you were locked out."

The CHAIRMAN. So you had it for 30 days after the lock-out.

Mrs. DUGAN. Not knowingly.

The CHAIRMAN. Not knowingly. How long was he unemployed after the lock-out?

Mrs. DUGAN. Since it was ruled a lock-out, he was able to collect unemployment. It was five or six months he collected unemployment, and then we had nothing coming in besides the \$35 a week for him pulling picket duty.

The CHAIRMAN. So you had limited or no income for several months; is that correct?

Mrs. DUGAN. Yes.

The CHAIRMAN. Was that after the unemployment ran out?

Mrs. DUGAN. Yes, sir.

The CHAIRMAN. And he was not getting this other income that you just mentioned—

Mrs. DUGAN. Unemployment?

The CHAIRMAN. He got unemployment. And then, did he have any other job?

Mrs. DUGAN. No, sir.

The CHAIRMAN. So it was just unemployment.

Mrs. DUGAN. When the unemployment ran out, all we had for those couple months was the \$35 a week. And he got a job offer through "networking", as they call it now, someone I knew. He had to travel two and one-half hours and live down there for six days a week and work ten-hour shifts on a power plant. A week and a half after he was down there, the wood scaffolding he was on cracked in half, and he fell 40 to 45 feet. From the sixth floor, God took him down to the fourth floor and laid him back in a corner on some sheet metal, which saved his life.

The CHAIRMAN. He fell that distance and he did not break any bones?

Mrs. DUGAN. No bones were broken.

The CHAIRMAN. Was he hospitalized after that?

Mrs. DUGAN. Yes, he was. He had lacerations of the forehead; his head was indented from the boards falling on top of him, across his chest and on his leg. Then, after he——

The CHAIRMAN. Was that covered by workmen's compensation?

Mrs. DUGAN. Yes, it was, sir.

The CHAIRMAN. And after he was released from the hospital, he continued to have pains in his chest?

Mrs. DUGAN. Yes. After a couple-month period of time, he complained of chest pains. They said it should have been over. I said, "We are not the type of people who want to milk the system. I have worked since I was 15 years old, with working papers. Randy is a good worker. We do not want a handout. We want good jobs," I said, "and we do not want to collect compensation."

So they found out he had some type of—they did a CAT scan due to infection in the leg, and he had, they thought, tumor-like, orange-size, on his lungs. And from there we had to go to Pittsburgh.

The CHAIRMAN. So he went back into the hospital, and was operated on; is that right?

Mrs. DUGAN. Yes.

The CHAIRMAN. And they found out that it was not a tumor, but it was a blood clot?

Mrs. DUGAN. It was blood clots.

The CHAIRMAN. And so the workmen's compensation covered the blood clots; is that correct?

Mrs. DUGAN. That is correct.

The CHAIRMAN. If it had been a tumor, would they have covered that?

Mrs. DUGAN. No, they would not have, and we would be stuck right now with—this is an estimate—\$13,000 worth of hospital bills.

The CHAIRMAN. So just on the quirk of whether it was a blood clot or a tumor, there was a difference of \$13,000 to you in terms of that?

Mrs. DUGAN. Yes.

The CHAIRMAN. Does that make any sense to you?

Mrs. DUGAN. No, it does not.

The CHAIRMAN. It should not make any sense to any person of logic.

Mrs. DUGAN. And for us to pay \$235.25 for health insurance a month, it is an impossibility. There is no possible way to pay that amount—

The CHAIRMAN. That is the cost of insurance, you mean, for you.

Mrs. DUGAN. That is what we got quoted in the mail from Blue Cross/Blue Shield.

When Randy recovered from this surgery, within three months we found that—the man who hired Randy had said, “You do not have to worry about a job. You have a job with us after this. You are a good worker.” And here, the Union is filing charges against the company for having temporary non-Union men. So in three months, after my husband is better, we will not be covered with compensation any longer.

The CHAIRMAN. OK. We want to welcome Senator Cochran, who is a recent addition to our Committee. We welcome him on our first day of hearings. We know everyone has a very full program and schedule, and we are delighted to have you here, Senator Cochran.

Senator COCHRAN. Thank you, Mr. Chairman.

The CHAIRMAN. Would members like to inquire of any of these witnesses? We will start off with Senator Stafford.

Senator STAFFORD. Thank you very much, Mr. Chairman. This is the first time I have had a chance in the last six years to refer to you as “Mr. Chairman”, and I am glad to have that chance to do so and say I think you have gotten off to a good start on a very important issue, health care and its costs in America.

I will not ask the witnesses questions. I think, Mr. Chairman, that you have explored the difficulties they have faced in detail and what they have told this Committee indicates to us the necessity for examining this question very carefully, and at least to the satisfaction of this Senator, it has demonstrated the necessity of doing something about catastrophic health costs in the United States.

The CHAIRMAN. Senator Pell?

Senator PELL. Thank you, Mr. Chairman.

I have no questions at this time except to say I am very glad of this opportunity to share in the anguish that these witnesses have demonstrated. It shows that there is so much misery and anguish in the world of which we are not aware, I think. What you see as you walk around in the community is you see the well people, the people who are working, and the people who are miserable or sick are more or less invisible. And there is a lot more of that misery than is apparent, I think, in our country, alas.

The CHAIRMAN. Senator Cochran?

Senator COCHRAN. Thank you, Mr. Chairman.

Let me respond first of all to your welcome to the Committee. I am delighted to be a new member of this Committee, because it gives me a chance to become more personally and actively involved in some of these issue areas that we will explore this week, as we look at the jurisdictional areas of interest to this Committee.

I commend you for calling the hearing, and I think that this Committee is obviously off to a quick start; I like that. These are issues that do need the immediate attention of the Congress. I hope that our Committee will soon present health care legislation to the

full Senate for debate and final approval. We must provide some genuine relief for those individuals who are health care consumers in this country, who cannot afford the costs that they are having to pay now, who are unable to get adequate insurance coverage for their health care needs. These are very serious problems, and I think the government needs to move more aggressively and quickly to try to address them.

I thank you for recognizing me in your comments. I appreciate that.

The CHAIRMAN. Thank you very much, Senator Cochran. Senator Simon?

Senator SIMON. First of all, I want to thank the witnesses, because what you have done is you have spoken for millions of other Americans, and you have done it very effectively, and I want to commend you.

Just a couple of comments, Mr. Chairman.

First, Mrs. Green, you mentioned about taking out the telephone. We have 7 million American homes that do not have a telephone; they cannot call somebody if somebody has a heart attack, they cannot call the police if somebody is trying to break in; they cannot call the fire department.

We should not tolerate that in this society, and you should not have to be threatened with the possibility of your phone being taken out.

Second, Mrs. Dugan, you mentioned about your husband falling on the scaffolding. Our rate of accidents and deaths from scaffolding is just far, far higher than other industrial countries. Japan, in the last ten years, has not had a single scaffolding death. We should not be having these things.

If I may ask one question to you, Mrs. Green, there are a lot of people on Medicare who, if they have to go in the hospital now, they have to pay \$520. They do not have it. If you were faced with having to go back again, you would have to pay \$520 just off the top.

Mrs. GREEN. No, thank God. We joined the Saint Joseph Hospital for \$25 each, and they pay for all of that now, for five years. We have up until 1990 to go into that, and all we would be responsible for now would be our doctor bills.

Senator SIMON. If I may ask you, then, as a follow-up, Mrs. Green, what if you needed glasses or a hearing aid—

Mrs. GREEN. Which we do. We have not had our teeth fixed; we have not been in ten years. We just need everything.

Senator SIMON. You need everything. What about dental care?

Mrs. Green' I would not look like I do today if I could go to the dentist.

Senator SIMON. In other words--and I do not mean to be picking on you, Mrs. Green—but the reality is you need dental care—you need dentures, do you?

Mrs. GREEN. Now. Like, I have needed them for years, yes.

Senator SIMON. And the reality is the people in our community who need dentures like you do, they just cannot afford it.

Mrs. GREEN. They have nowhere to go, no.

Senator SIMON. Nowhere to go. We can get a man to the moon, but we cannot get dentures to Mrs. Green.

Mrs. GREEN. That is right. They have a dental school that just charges you a small amount, but people like us to not have the small amount. They say they charge one-third of the regular price, which is wonderful if you can pay that third. But if they are down, like we are, you cannot pay that.

Senator SIMON. I thank you very much.

Thank you, Mr. Chairman.

The CHAIRMAN. Senator Adams?

Senator ADAMS. Thank you, Mr. Chairman.

I appreciated very much your welcome to the Committee. I am very pleased to have the opportunity to serve on it, and I want to join with the other members in thanking the panel. In particular I am very pleased that we started with citizens explaining exactly what their problems are. It shows what a gap we have in our society in being able to take care of the health care needs of all our citizens. You speak not only for yourselves but for millions of others. Mr. Chairman, I commend you for calling these hearings, and I look forward to working with you on legislation to address the catastrophic health problems that these witnesses have demonstrated so well.

Mr. Chairman, I would also like to ask permission of the Chair to place a statement in the record at the appropriate point.

The CHAIRMAN. Thank you very much, Senator Adams. We will be glad to include it.

I, too, want to thank our panel. What we have recently seen, as the Secretary of HHS introduced legislation dealing with catastrophic health for the elderly, what we have seen here is that there is a catastrophic need for the young as well. And the fact is that even if you had catastrophic, you would not be dealing with some of the particular needs that Mrs. Green has identified in terms of the medicine, eye care, dental care, foot care, which are essential in terms of the quality of life.

The fact is that all of these people are hardworking men and women of our country who have worked a lifetime and are living in fear. And the tragic element is that not only are they facing this, but there have been 8 million additional people who have fallen into the class of having no health insurance or completely inadequate health insurance just since 1980.

There are 8 million new Americans who are living in that great fear, and that is something that we as a society have to deal with, I believe. And, as our colleagues have mentioned to you, your presence here and telling us these stories, I think, will impress our colleagues, as I am sure they do the American people.

We know it is always difficult to talk about health problems. We like to keep these matters quiet; we always feel it is a matter of personal concern for our families. I know that that is a very deeply-rooted tradition in our society. And so we are very especially thankful that you have been willing to share these very intimate thoughts and moments and needs with our Committee, and I think quite frankly it should put a very heavy responsibility on all of us who have heard it, and hopefully, those that will read about it, a very important responsibility to do something about it. And you certainly have that commitment from me, and I am sure I speak for many others as well.

I want to thank you all very much.

Mr. Muir?

Mr. MUIR. Yes, I wanted to add one thing. Mrs. Gates is at, what, \$9,800 income, and she does not qualify for the State Medicare or whatever it is. And here we are, we are making, like I said, \$36,000 together, and with the bill that we face, we could not catch up on the interest on that, and we do not know if we are going to qualify for it. And then where does that leave us, you know? That is the question.

The CHAIRMAN. That is right. We are talking here about working families, and it could happen to any family. And as we know, although we are not going to get into it today, there is pretty much of an exemption in terms of the first ten days for well-baby care, in any event, under most of the insurance policies.

But we ought to be able to provide. People are not asking for very much, but we have all got different kinds of health insurance, as Mrs. Green. Imagine waiting to get attention to their health care needs until they turn 65 to qualify for Medicare.

So we want to thank you all very much, and if any other thoughts come to your mind—yes, Mrs. Green?

Mrs. GREEN. I would like to say something. We tried to get food stamps, and they told us that we were making \$70 too much.

The CHAIRMAN. Well, hopefully, we will come to grips with some of those really nonsensical limitations which further depress people not only in getting adequate food, but are skewed in such a way, to the point of irrationality. That is something that I hope the Congress will come to grips with. There are so many illustrations of them, and we ought to be about the business of doing it.

I want to thank you all very much.

We will have about a one and one-half-minute recess while we excuse this panel and bring up our next witness.

[Pause.]

The CHAIRMAN. We will be in order.

Our next witness is Mr. Joe Califano, the former Secretary of HEW. Since his service there, he has continued a profound interest in the whole issues of health care, quality of health care, access to health care, research, and health policy generally. He has been a counsel to many of the largest and most successful companies and corporations who have been dealing with this issue and experimenting and thinking a good deal about the public policy issues and questions which we will be facing to try and achieve good quality health care for the American people.

We are very grateful for him to come back to this Committee. He appears not as a stranger, but as a friend. He has appeared before this Committee on a number of different occasions at different times with different chairmen. We are always glad to have you before us, and we look forward to your testimony.

STATEMENT OF JOSEPH A. CALIFANO, JR., FORMER SECRETARY OF HEALTH, EDUCATION AND WELFARE; PARTNER, DEWEY, BALLANTINE, BUSHBY, PALMER & WOOD LAW FIRM; CHAIRMAN, HEALTH COMMITTEE, CHRYSLER CORPORATION AND AMERICAN CAN CO., WASHINGTON, DC

Mr. CALIFANO. Thank you, Mr. Chairman. I greatly appreciate the chance to testify. I will only use part of my statement. As you indicated, I would like to file the entire statement for the record.

The CHAIRMAN. Fine. It will all be filed in the record.

Mr. CALIFANO. Let me congratulate you, Mr. Chairman, for assuming the leadership of this Committee whose work is so critical to so many of our people.

It is fitting that you have chosen health care as the subject of your first hearings, since for 25 years you have been one of the foremost leaders of our nation in the quest to assure health care to every American on the basis of their need rather than their ability to pay.

It is also fitting because, in thinking about the testimony that has just been presented, I would characterize our health care system as a pothole system of health care, with potholes in Medicare and potholes in Medicaid, potholes for people that are employed and periods when they are not employed. And they are savage potholes because they actually damage our people and shatter lives.

The American health care system, Mr. Chairman, is both miraculous and mercenary. We have the most advanced medical technology on this earth, an abundance of specialists, hundreds of distinguished hospitals, any one of which would be the envy of capitals of the world.

Our achievements have come at astronomical cost--some \$460 billion in 1986, almost 11 percent of gross national product. That is a greater proportion of our gross national product than any other nation in the world spends on health care.

There have been encouraging signs in dealing with our costs. We have begun to reduce excess utilization, particularly in hospitals. But the rate of expenditure continues to rise rapidly. In 1986, price escalation for medical care was six times that of the increase in the overall consumer price index.

Mr. Chairman, by any measure, we in America have the most expensive health care system in the world.

Now, the world's most expensive health care system might be justified if Americans were the world's healthiest people. But while the United States spent \$1,600 for the health of each person in 1984 and Singapore spent about \$200, both nations have the same life expectancy at birth. And Singapore's appears to be rising more rapidly than ours.

The world's most expensive health care system might be justified if it were a fair system that provided care to all our citizens. But millions of our citizens still lack adequate health care. And while there have been marked improvements in life expectancy and infant mortality for blacks, there are still gaping disparities between blacks and whites in life expectancy, infant mortality and health status generally.

The world's most expensive health care system might be justified if it were buying more health insurance for all our citizens. But since 1979 the number of Americans under 65 without health insurance has jumped from 29 million to 37 million, a rate of more than one million Americans a year. And in 1984, the Department of Health and Human Services concluded that, in addition to those who have no health insurance for at least part of the year, another 16 million had inadequate health care coverage.

Our prospects for a healthier America must rest on three strong legs. The first leg is prevention; the second is access; and the third is reasonable cost.

Prevention: 67 percent of all disease and premature death is preventable. Yet, in 1985, less than one percent of the federal government's—

The CHAIRMAN. State that statistic again.

Mr. CALIFANO. Sixty-seven percent of all disease and premature death is preventable. Yet, in 1985, less than one percent of the federal government's \$125 billion health care budget, and less than three-tenths of one percent of total national health expenditures, went for health promotion and disease prevention. Our greatest need is for sophisticated health—

The CHAIRMAN. So what you are saying is 67 percent of the deaths, premature deaths are preventable, and that we are doing very little about this in terms of health promotion and disease prevention. I think it is a very, very significant and important point. You might just mention what that statistic is, the amount that we are actually expending in terms of health promotion and disease prevention in relationship to the total amount that we are spending.

Mr. CALIFANO. Well, of the \$125 billion that government spent, we spent less than one percent. We spent about a billion dollars for health promotion in 1985.

It is worse when you take the whole picture. It is less than three-tenths of one percent of that total \$460 billion figure. It is a little over \$2 billion out of over 460.

Let me just give one example, Mr. Chairman: heart disease. It is America's number one killer, and our people have the impression that coronary bypass surgery, modern cardiopulmonary techniques, miracle pills and human heart transplants are the way to battle heart disease. That could not be more wrong.

Since 1970, our nation has experienced a dramatic 25 percent decline in deaths from coronary heart disease. The major reasons are two: improved eating habits and the decline in smoking. Those two items have accounted for more than half of that dramatic decline in deaths from coronary heart disease.

There are two key areas, Mr. Chairman, I would like to mention in the prevention area where the government has not even tapped its potential: addiction and cancer. Last fall, Congress, reacting to the crack epidemic, passed major new legislation aimed at curbing drug abuse. There are some hopeful signals in the bill, including an increase in funds for treatment and prevention over the next five years.

But what I think we need is a fundamental national commitment to attack the roots of addiction on a scale and with the quality of

effort we have mounted against cancer and heart disease. The centerpiece of that commitment should be a National Institute on Addiction, alongside the National Cancer Institute and the Heart, Lung and Blood Institute.

Just stop and think; addiction in all its forms is our top national health problem. Tobacco use and alcohol and drug abuse cause at least 600,000 needless deaths each year at an annual economic cost of over \$150 billion. A National Institute on Addiction could take on the research work of some present institutes and look at all addictive substances and multiple drug abuse. It would generate the steady stream of funds necessary to study addiction, make clear that we are serious about it, provide the basic research essential to nourish efforts in the private sector, and attract our best and brightest to the effort, just as we have with the National Cancer Institute.

Millions of our people spend billions of dollars to get and stay hooked on everything from cigarettes to crack. And all the huffing and puffing and all the police, prisons, and electrocutions are unlikely to change that grim reality. A major research effort just might.

The other area, Mr. Chairman, I would like to mention, is cancer screening, a very simple thing. Screening can reduce breast cancer mortality by 30 percent among women over age 50, yet only 15 percent of our women have such annual examinations. Cervical cancer screening through the Pap smear, a simple test, can reduce mortality by 75 percent, but only about half the women ages 40 to 70, the high-risk group, avail themselves of that procedure.

In addition, Mr. Chairman, I think government must play a vigorous role in enforcing clean air and clean water laws and setting up and enforcing tough safety and smoke-free space standards in public areas and the workplace.

We saw these witnesses this morning. The second leg of a healthier America, Mr. Chairman, is access, a problem to which you have devoted much of your public career. Good health is not a right, but access to good health care is a right. No just society can deny that right to its citizens, deny them the right to the health care they need. We in America have done that for far too long. We are the only industrial society in the world that does not recognize health care as a fundamental right of each of the human beings who are our citizens.

Thirty-seven million Americans—three-fourths of whom are employed or the dependent of an employed person—are without health insurance for all or part of a year. Typically, they work for low wages in small businesses with few employees. Almost half of the uninsured are married and over 30 years old. Sixty percent of the uninsured, Mr. Chairman, work full-time.

The number of uninsured jumped 30 percent between 1980 and 1985. When those with inadequate insurance are added, we are talking about more than 50 million Americans who each year face problems in getting access to health care. So these people you had here this morning do, as you and other members of the committee indicate, represent millions of Americans around the country.

The physical and psychological and financial burdens fall most savagely on the uninsured and their children and spouses. But the

costs are shared by all of us, and especially companies that do provide health insurance for their employees. Medicare and Medicaid programs will not pay any portion of a hospital's bad debts or charity care, so when an uninsured person cannot pay, that cost is shifted to private payers. Most often, hospitals have simply folded the cost of uncompensated care into their overall costs and then passed it along to private payers—individuals, commercial insurers, self-insuring corporations and Blue Cross.

The total annual cost of uncompensated care is more than \$8 billion, a large portion of which represents additional costs to companies that do provide health benefits to their employees. These costs add unfairly to the competitive disadvantage that many of these companies already face in the international marketplace.

To address the problem, Mr. Chairman, I suggest we build on the best of our health care system. We do not need a big bureaucracy, we do not need burdensome regulations, and we do not need a big budget increase to do this job. What we need is a minimum health care law, just as we have a minimum wage law. The right to health care is as fundamental as the right to a decent wage for a working man or a working woman.

Most Americans, about 145 million, have their health coverage through their employment relationship. Let us build on that achievement. Let us simply require that each employer assure its employees of a minimum level of health care: physician treatment, hospitalization, preventive services for the employee and his or her family. The employer could provide that care however it wished: through insurance, a health maintenance organization, preferred provider contracts, or directly. But the employer would have to pay only the cost of such coverage under the least expensive and most efficient plan. Other plans could, of course, be offered. If the employer did not choose to pay the extra expense, the employee would have to pay the difference. This would encourage competition in the marketplace, press employers and workers to seek the best plan at the lowest cost, and it would not add to the federal budget.

For small employers and the self-employed, a mechanism should be developed to provide competitive group rates and access to health maintenance organizations and preferred providers. Currently, Mr. Chairman, small businesses face premiums as much as 40 percent higher than those paid by large companies.

All employers would, of course, remain free to provide greater health care benefits, and unions would, of course, have the right to bargain for them.

The third leg of a healthier America is reasonable cost. The continued rise in health care costs threatens our ability to maintain even current levels of care. While business and government have been working successfully to reduce utilization, to cut hospital admissions and lengths of stay, while that has been going on, hospital prices, doctors' fees, and prescription drug prices have been shooting up at six times the rate of price increases for all goods and services. In the year ending November 1996, the consumer price index for medical care rose 7.7 percent, while the overall consumer price index rose only 1.3 percent. In effect, as we reduce utilization, we are paying an inflated price for each service.

And you will recall, Mr. Chairman, several years ago you tried to cap hospital costs because medical care costs were rising at just twice the rate of the consumer price index.

Americans have had a higher rate of increase in health care expenditures during the last five years than at any time, in real dollars, in the history of this country. We have got to take a host of actions to make our system more efficient. Some include closing half the hospital beds in this country, overhauling our medical malpractice system, redesigning health insurance and Medicare to pay for services in less expensive settings, as well as to pay for catastrophic care, paying for home health care and outpatient care. Above all, Mr. Chairman, we must not be lulled into thinking that we have solved the cost problem. The battle has only begun and the outcome is very much in doubt.

Mr. Chairman, let me just close by congratulating you and the members of this Committee, both sides of the aisle, for holding these hearings and for opening on the subject of health care.

[The prepared statement of Mr. Califano follows:]

STATEMENT OF
JOSEPH A. CALIFANO, JR.*

BEFORE

THE COMMITTEE ON LABOR AND HUMAN RESOURCES
OF THE U.S. SENATE

January 12, 1987

* Mr. Califano was Secretary of Health, Education and Welfare from 1977 to 1979, and President Lyndon Johnson's assistant for domestic affairs from 1965 to 1969. He is presently senior partner in the Washington office of the law firm of Dewey, Ballantine, Bushby, Palmer & Wood, and chairman of the health care committees of Chrysler Corporation and American Can Company. His most recent book, America's Health Care Revolution: Who Lives? Who Dies? Who Pays?, was published by Random House in 1986.

Mr. Chairman, Members of the Committee:

Mr. Chairman, I greatly appreciate the opportunity to testify at your first hearing as Chairman of this committee. I congratulate you for assuming the leadership of this committee, whose work is so critical to so many of our people.

It is fitting that you have chosen health care as the subject of your first hearings, since for 25 years you have been one of the foremost leaders of our nation in the quest to assure health care to every American on the basis of their need rather than their ability to pay.

It is also fitting because a revolution in the American way of health is under way, and it is likely to be as far-reaching as any economic and social upheaval we have known. At stake is who gets how much money out of one of America's top three industries, who suffers how much pain, how long, and who gets the next available kidney, liver or heart: In short, who lives, who dies and who pays.

The American health care system is both miraculous and mercenary. We have the most advanced medical technology on this earth, an abundance of superb specialists, and hundreds of distinguished hospitals, any one of which would be the envy of the capitals of the world.

Our achievements have come at astronomical cost -- some \$460 billion in 1986, almost 11 percent of our Gross National Product. That's a greater proportion of gross national product than any other nation in the world and it's

more than the total national product of all but a handful of countries.

There are some encouraging signs -- we have begun to reduce excess utilization, particularly in hospitals. But the rate of expenditure continues to rise rapidly, and in 1986 price escalation for medical care was six times that of the increase in the overall consumer price index. By any measure we in America have the most expensive health care system in the world.

The world's most expensive health care system might be justified if Americans were the world's healthiest people. But, while the United States spent \$1600 for the health care of each person in 1984 and Singapore spent about \$200, both nations have the same life expectancy at birth. And Singapore's appears to be rising more rapidly than ours. Singapore and six other nations have infant mortality rates lower than ours.

The world's most expensive health care system might be justified if it were a fair system that provided care to all our citizens. But millions of our citizens still lack adequate health care, and, while there have been marked improvements in life expectancy and infant mortality for blacks, there are still gaping disparities between blacks and whites in life expectancy and health status.

The world's most expensive health care system might be justified if it were buying more health insurance for all our citizens. But, since 1979 the number of Ameri-

cans under 65 without health insurance (during all or part of the year) has jumped from 29 to 37 million, a rate of more than one million a year. In a 1984 study, the Department of Health and Human Services concluded that in addition to those who have no health insurance for at least part of the year, another 16 million had inadequate insurance coverage.

Our prospects for a healthier America must rest on three strong legs. The first leg is prevention -- it saves far more lives than all our high-tech equipment and specialists, at a fraction of the cost. The second leg is access -- we must provide essential care to those millions of our citizens who at best get catch-as-can care from those hospital emergency rooms willing to treat them, or at worst, and far too often, no care at all. The third leg is reasonable cost -- the soaring cost of care threatens to deny even the affluent access to the miracles we have come to expect.

Prevention. Sixty-seven percent of all disease and premature death is preventable. Yet, in 1985, less than one percent of the federal government's \$125 billion health care budget and less than three-tenths of one percent of total national health expenditures went for health promotion and disease prevention. Our greatest need is for sophisticated health promotion programs. The plain fact is that each of us can do more for our own health than any doctor, any hospital, any machine, or any drug.

For example, heart disease is America's number-one killer. People have the impression that coronary bypass surgery, modern cardiopulmonary techniques, miracle pills and human heart transplants are the way to battle heart disease.

Right?

Couldn't be more wrong.

Since 1970 our nation has experienced a dramatic 25 percent decline in deaths from coronary heart disease. The major reasons? Improved eating habits - the reduction of cholesterol - and the decline in cigarette smoking were responsible for more than half of the decline in deaths from heart disease.

Virtually all factors that substantially increase likelihood of heart disease are within the patient's, not the doctor's, control: smoking, alcohol and drug abuse, a high-cholesterol diet, obesity, lack of exercise, stress.

In a free country, pursuit of a healthy lifestyle is voluntary. But we can certainly take a host of actions to encourage Americans to choose wisely, and to bear the cost when they don't.

Americans are beginning to wake up to the potential for creating a healthy nation. One of the most ambitious corporate efforts is Johnson & Johnson's Live for Life program which offers employees help in smoking cessation, weight control, nutrition, exercise and stress management. The results are impressive: a 25 percent drop in

smoking, an 11 percent increase in heart efficiency, a three point drop in blood pressure and a 15 percent drop in absenteeism in plants with the program. And a report just published in the Journal of the American Medical Association found that over a five-year period, the Live for Life program cut hospital cost increases by 50 percent.

In 1985, Blue Cross and Blue Shield of Indiana reported on five year's experience with its "Stay Alive and Well" program that offered screening and intervention to reduce the risk of heart disease, cancer, and stroke. The program produced on average savings in health insurance claims of \$143.60 per employee, measured against an average cost of \$98.96.

Last year the Henry J. Kaiser Family Foundation, of which I am a trustee, launched a Community Health Promotion Grant Program designed to substantially reduce five major health problems -- heart disease, drug and alcohol abuse, teenage pregnancy, cancer, and injuries -- by encouraging changes in personal behavior and societal practices. The Foundation will target at least \$15 million over the next three years to create a climate in each participating community that helps people to choose healthy behaviors and reject risky ones, and to show how much health can be improved through such projects.

In prevention, there are two key areas where we haven't even tapped government's potential: addiction and cancer. Last fall, Congress, reacting to the epidemic of

crack, passed major new legislation aimed at curbing drug abuse. There are some hopeful signals in the bill, including the first increase in funds for treatment and prevention in five years, which I hope will be continued despite the Administration's budget proposal for Fiscal 1988.

What we need, however, is a fundamental national commitment to attack the roots of addiction on the scale and with the quality of effort we have mounted against cancer and heart disease. The centerpiece of that commitment should be a National Institute on Addiction alongside the National Cancer Institute and the Heart, Lung and Blood Institute.

Addiction in all its forms is our number one health problem. Tobacco use and alcohol and drug abuse cause at least 600,000 needless deaths each year at an annual economic cost of more than \$153 billion. A National Institute on Addiction could take on the research work of the present National Institutes on Drug Abuse, Mental Health, and Alcohol Abuse and Alcoholism, and look at all addictive substances and multiple drug abuse. It would help generate the steady stream of funds necessary to study addiction, make clear that we're serious about it, provide basic research essential to nourish efforts in the private sector and attract our best and brightest to the effort.

Millions of our citizens spend billions of dollars to get and stay hooked on everything from cigarettes to crack. All the huffing and puffing and all the police,

prisons and electrocutions are unlikely to change that grim reality. A major research effort just might.

Another high-return prevention activity for government is cancer screening. Screening can reduce breast cancer mortality by 30 percent among women over age 50, yet only 15 percent of such women have annual examinations. Cervical cancer screening through the Pap smear can reduce mortality by 75 percent, but only about half of the women ages 40 to 70, the highest risk group, avail themselves of the procedure. In addition, government must play a vigorous role in enforcing clear air and clear water laws, and setting up and enforcing tough safety and smoke-free space standards in public areas and the workplace.

Access. Prevention should be our first line of defense against medical problems, but no one should be denied access to essential care when they need it. Good health is not a right, but access to good health care is. No just society can deny the right of its citizens to the health care they need. We in America have done that for far too long. We are the only industrial society that does not recognize such a right.

Thirty-seven million Americans -- three-fourths of whom are employed or a dependent of an employed person -- are without health insurance for all or part of a year. Typically they work for low wages in small businesses with less than 25 employees. Almost half of the uninsured are

married and over 30 years old. About 60 percent are employed full-time.

The number of uninsured jumped 30 percent between 1980 and 1985. When those with inadequate insurance are added, more than 50 million Americans each year face access problems.

The physical, psychological and financial burdens fall most directly on the uninsured and their children and spouses. But the costs are shared by all of us, and especially those companies that do provide health insurance for their employees. The Medicare and Medicaid programs will not pay any portion of a hospital's bad debts or charity care, so when an uninsured person can't pay, that cost is shifted to private payers. Most often hospitals have simply folded the cost of uncompensated care, whether rendered voluntarily or in the form of bad debts, into their overall costs and then passed it along to private payers -- individuals, commercial insurers, self-insuring corporations and Blue Cross.

The total annual cost of uncompensated care is more than \$8 billion, a large portion of which represents additional costs to companies that provide health benefits to their employees. These costs add to the competitive disadvantage many firms already face in the international marketplace because of waste and inefficiency in the health care system.

To address this problem, we should build on the best of our health care system. We don't need a big bureacracy or burdensome regulations. What we need is a minimum health care law just as we have a minimum wage law. Most Americans, about 145 million, have health care coverage through their employment relationship. Let's build on that achievement. Let's simply require that each employer assure its employees of a minimum level of health care: physician treatment, hospitalization, preventive services for the employee and his or her family. The employer could provide that care however it wished: through insurance, a health maintenance organization, preferred provider contracts, or directly. But the employer would have to pay only the cost of such coverage under the least expensive plan. Other plans could of course be offered. If the employer did not choose to pay the extra expense, the employee would have to pay the difference. This would encourage competition in the marketplace, and press employers and workers to seek the best plan at the lowest cost.

For the small employers and the self-employed, a mechanism should be developed to provide competitive group rates and access to health maintenance organizations and preferred providers. Currently, small businesses face premiums as much as 40 percent higher than those paid by large companies.

All employers would of course remain free to provide greater health care benefits, and unions would have the right to bargain for them.

Reasonable Cost. The third leg of the stool is reasonable prices and reasonable costs. The continued rise in health care costs threatens our ability to maintain even current levels of health care. While business and government have been working successfully to reduce hospital admissions and lengths of stay, hospital prices, doctors' fees and prescription drug prices have been shooting up at six times the rate of price increases for all goods and services. In the year ending November 1986, the consumer price index rose 7.7 percent for medical care while the overall consumer price index rose only 1.3 percent. In effect, as we have reduced utilization, we pay more for each service.

These trends are reflected in overall health spending as well. A study by Professor Uwe Reinhardt of Princeton University shows that, in real dollars, we have had a higher rate of increase in health care expenditures during the last five years than at any time in the history of our nation. The preliminary projections for 1987 are ominous. At Chrysler Corporation, where we spent \$58 million less than planned for health care in 1984, price inflation presents a risk of our spending up to \$31 million more than planned in 1987.

We must take a host of actions to make our system more efficient. Some of these include closing half the

nospital beds in this country, overhauling our medical malpractice system, redesigning health insurance and Medicare to pay for services in less expensive settings, such as home health care and outpatient care, and adopting case management systems. Above all, we must not be lulled into thinking we have solved the cost problem. The battle has only begun and the outcome is still very much in doubt.

Mr. Chairman, once again I congratulate you and the members of your committee for holding these hearings and on your commitment to the vulnerable in this country. More than ever before, your leadership is needed.

I'll be glad to answer any questions you may have.

The Chairman: Thank you very much, Mr. Cazzavos, for your excellent presentation.

As I understand, to be correct, I would like to just touch very briefly on one question in each of those areas, then yield to my colleagues.

Let us take the biomedical research. It is my understanding that both through prevention and better treatment you could reduce probably the instance of cancer up to 30 percent by the year 2000. What we are talking about is the kind of actions which you have indicated have been taken in terms of diet, which is the personal kinds of accountability, plus the kinds of tests that you have illustrated here, plus using the better techniques in the treatment of it. We are not talking about this as being a major new expenditure, but something that can have a very important impact.

Mr. Cazzavos: That is right, Mr. Chairman. I think you hit on two very important points. One, each of us can do more for our own health than any doctor, any hospital, any machine or any drug by just watching our diet, quitting smoking, drinking in moderation, getting exercise, handling stress. And these are things which people have to be educated about—one of the areas of jurisdiction of this Committee is in the education area—and educated at it at a young age. There is no expense to that.

The other one, and you are right, those tests are very simple tests. The earlier we detect cancer, the far greater likelihood we have of eliminating it, and the kinds of tests that you are talking about are very inexpensive and can be offered in very simple settings. For example, every large company in this country, for example, in my judgment, ought to provide the kind of cancer screening to its employees that you have discussed and I mentioned in the statement.

The Chairman: Let me ask you something about the Administration and Secretary Bowen's proposal to expand the Medicare catastrophic illness. Have you thought about that? Have you studied it?

Mr. Cazzavos: I have, Mr. Chairman. I think it is a superb proposal. I agree with you that it is outrageous for Secretary Bowen to come forward with that proposal, and I hope that the Congress will act on it. It is long overdue.

The Chairman: I am sure we will be hearing some comments on that later on in the hearing. I could not help but be struck about the sense of need, not only for those that are older, but also those who are the working people of this country, men and women that are working people who are plagued by similar kinds of problems in the health care system.

One of the programs which developed in recent times and has been thought about for some time and put into place in the most recent times is the DRG, prospective budgeting for hospitals. Could you tell us about your own reaction to the Administration's DRG proposal, Diagnostic Related Groups, and their attempt to tie and cap hospital costs, and how you react to it, what your own thinking is about what the implications have been in terms of the actions which you have outlined?

Mr. Cazzavos: Mr. Chairman, I think the DRG program is, in and large, a good program. I think it is incomplete. I think that it is important to hold down hospital costs, as every President since

Lyndon Johnson has tried to do in one way or another, regardless of party or ideology. The DRG system does that.

But I think it is incomplete in a couple of senses: One, when you let people out of the hospital that soon, you have got to provide lesser levels of care for them. You have got to cover home care, or you have got to cover nursing home care or some kind of "motel-type" care, as they say, for individuals. It is much less expensive, but they should not be denied that care.

Secondly, I think in the short run it resulted in a significant escalation in the costs in the private sector because it took awhile for the large private insurance plans to impose the same caps, and the hospitals were able to transfer those costs.

And, lastly, I hope the Administration will go forward with its proposals to, in effect, enfold doctors—at least hospital-based doctors—under the DRG system and look, as you indicated and Senator Hatch indicated, at outpatient care. Because the reality is that in many parts of this country today, it costs more to have cataract surgery in a doctor's office than it does in a hospital; because in the doctor's office there is no cap. There is no DRG. There is no limit. And we have to begin looking at that, and I hope this Committee will in the course of its deliberations.

The CHAIRMAN. Just finally in this first round, one of the very strong national commitments that was made in the last Congress, bipartisan, was to try and do something about the whole drug infestation in our schools and communities. To summarize what we were attempting to do: one, was interdiction; two, prosecution, we fast tracked the prosecution availability, follow the career criminal procedures which we had passed previously; three, education and rehabilitation, those seem to me to be the principal elements of it.

With the budget reductions the President has proposed in these areas of education and rehabilitation.

What kind of message do you think that that sends to families? Do you think it expresses the priorities of the American families in funding reductions of 50 percent or more?

What kind of signal does it send and what is your reaction?

Mr. CALIFANO. I think the kind of signal it sends is that, as far as drugs are concerned, we are going to saw one leg off ourselves in the race. It recognizes drug abuse as the number one crime problem in the country, and it is the top crime problem.

If you take alcohol in addition to the hard drugs, most crimes, an enormous number of crimes are committed because of drugs and because of people under the influence of drugs.

It fails to recognize that addiction is also our top health problem; and if we are serious about dealing with it, we will deal with that. And we will deal in the schools in the youngest grades. As you indicate, it sends a terrible signal from the government. And if the government is not going to provide the leadership here, the private sector is not going to jump in the way they should.

I will give one simple private sector example. It is incredible to me that you can watch children's cartoons on a Saturday morning and not see one single ad or promotion dealing with drug abuse. That is the age at which to start educating those kids about that instead of educating them about sugar cereal or toys or whatever else they are being educated on.

In the government sector, addiction is an incredibly difficult problem to deal with. It is as intractable as cancer, and my suggestion here that the Committee look at the possibility of creating a National Institute on Addiction is because to get our best minds working on a problem that intractable, we have got to give them some sense that if they devote many, many years of their life to it, there will be funding there, there will be research there, there will be a national commitment to deal with it. And I hope that we do that.

The CHAIRMAN. Senator Cochran.

Senator COCHRAN. Thank you, Mr. Chairman.

It was interesting to hear your observation regarding the disparity of costs of health care insurance between large employers and small employers. Why do small businesses have to pay 40 percent more for coverage than large businesses?

Mr. CALIFANO. Because they have a smaller group of employees and they do not have the ability to spread the risk over larger numbers of employees. That is the largest single reason, and so the insurance company views it as an economic matter. And if one of five people gets terribly sick, they have got to have a lot of money to cover that; where if one of five thousand people get sick, they can spread it over a lot more people. That is the main reason for that.

Senator COCHRAN. What would the impact be on small business if this Committee adopted or recommended to the Senate that we adopt legislation that would require employers to furnish health care coverage to all their employees? Would we inadvertently put out of business a lot of small business people?

Mr. CALIFANO. No. I think, Senator, you put your finger on an important issue. I think that if this Committee adopted something like a minimum health care law, as we have a minimum wage law, you would have to as part of it provide legislation to create some mechanism to assure small businessmen that they could acquire insurance at the same rates at which large businesses do. That could be done by insurance companies pooling, by small businesses pooling together. But it does not require a big bureaucracy, and it would not require much money.

But you would have to do that; otherwise, you would create a problem for small businesses.

Senator COCHRAN. Even though you say that there would be no impact on the budget, and I agree with you, if you would have a requirement of that kind but the impact could be indirectly one that would have budgetary consequences. We see the unemployment numbers coming down now below seven percent. People are going back to work; hundreds of thousands of new jobs are being created in our economy today. But would this get reversed if we overload small business with a lot of requirements if we pushed the minimum wage up, if we pushed the requirement to provide high cost health insurance that they are not now required?

Mr. CALIFANO. I guess I think two things. One, as I said, you would have to create a mechanism so that small businessmen would have access to the same favorable rates that large corporations have.

Senator COCHRAN. How do you do that, though? It is easy to say, but how do you do it?

Mr. CALIFANO. Well, there are a couple of ways. You could do it by providing for a consortium of insurance companies to spread the risk among small businesses. You could do it by creating a quasi-government corporation like a Fannie Mae in this area. There are lots of ways you could do it which would not impact on the federal budget.

In terms of jobs and employment, it is true that unemployment is going down. But unprecedented in our history, as unemployment goes down, there is a decline in the number of people covered by health insurance. What is the reason for that? People are losing jobs in the industrial sector where they had good health insurance coverage—United Auto Worker plans and Steelworker plans—and going into a service sector where there is either no health care coverage for them at all or very inadequate health care coverage. That is unprecedented.

So there may be more jobs, but there is a difference between a job that pays \$15 an hour or \$10 or \$12 an hour, and provides health insurance for the man and his wife and his children, and a job that pays \$3.50 an hour and provides no health insurance coverage.

Senator COCHRAN. You mentioned that you would recommend closing half of our hospital beds or closing half of our hospitals? I did not understand which.

Mr. CALIFANO. Well, I think immediately I would close about four to five hundred thousand beds, and over the next five to ten years I would close half of the hospitals.

Recognize that as a result of the Administration's efforts with the DRG system and related private efforts, we are talking about hospital occupancy rates in this country that are now running at 60 percent of capacity. If that were a business, that businessman would sell off the excess property or the excess plant and run a much more efficient operations. Hospitals have not done that to the extent that they should.

I do not minimize the difficulty of doing this, because anybody in this area will tell you there are excess beds and excess hospitals. The problem is they are all in somebody's else state or district or neighborhood.

Senator COCHRAN. Well, very few of them are in my state.

Mr. CALIFANO. I know that.

Senator COCHRAN. Our problem is one of providing access to low income individuals in many small communities, rural areas, where they do not have access to not only hospital beds, but diagnostician attention, other fundamental health care services that are desperately needed in the small rural areas.

What would you suggest for us to consider in terms of trying to make more readily available to low income persons in rural areas the health care that people do have access to in the metropolitan areas?

Mr. CALIFANO. The one inexorable rule of health care that we have learned over the last 40 years, as corporations provided insurance for their employees, as the government passed Medicare and Medicaid, is that health care services will follow reimbursement.

And if you had a minimum health care law and those low income people had some coverage, and doctors and nurses could get reimbursed for providing care, believe me, you would find plenty of them in Mississippi, in those rural areas providing care. Because there is no question that whatever else we know about health care in this country, we know that health care will follow reimbursement for the services.

Senator COCHRAN. Thank you, Mr. Chairman, for the opportunity to question the witness.

The CHAIRMAN. Senator Pell.

Senator PELL. Thank you, Mr. Chairman.

I was very struck, Mr. Secretary, with your original statistics that you cited. I would like to read into the record the countries that do better than we do when it comes to health care, at least in longevity, which is the bottom line. Those figures are life expectancy at birth. Japan is first with a life expectancy of 74.8 years, then Switzerland, Iceland, Israel, Netherlands, Norway, Panama, Australia, Cuba, West Germany, and then the United States. And as you pointed out, we pay more than any other nation for our health care.

What can we do about it? That is the question we must confront. Canada, whose health care delivery system is sort of a cross between the British system and our system, seems to have worked out a reasonable compromise. Would you advocate going the Canadian route, going the British route, or staying as we are? What would be your own broad thoughts in this matter?

Mr. CALIFANO. I think, Senator Pell, I would really build on the system we now have. The British system, in which the government owns all the hospitals and the doctors, by and large, work for the government, came about at the end of World War II when the voluntary hospital system had been taken over, the Government for the war effort and all the doctors and nurses were in the armed forces, so it was easy to do that.

Here, I think we should use the employment relationship to provide adequate health care for most of our people; and for those that do not fall into that relationship, we should use Medicare and Medicaid. Personally, I would combine them into one program. But I would not have the gaps, what I call the savage potholes of Medicare and Medicaid, some of which you saw today: a woman who is ineligible for Medicaid because she is not a single parent with minor children; a couple that is ineligible for health care because they are not single parents and because they happen to make a little bit too much income.

That is the course I would follow.

Senator PELL. Do you think that one of the reasons for the expense of our system is the emphasis we put on the terminal cases, where we keep people alive far longer than in other countries? I think in Great Britain, for example, my recollection is one does not receive kidney dialysis after a certain age. You do not get bypasses after a certain age.

Is it that rather cruel and arbitrary method that keeps costs down, or is it some other thing?

Mr. CALIFANO. Personally, I believe that if you take that \$460 billion, at least \$110 to \$125 billion are wasted. Those dollars are spent on medical procedures that simply are not needed.

Senator PELL. You mean defensive medicine, as you pointed out earlier?

Mr. CALIFANO. Not just defensive medicine. The practice of medicine in this country is incredibly erratic. I mean, if you just take the state of Massachusetts where Senator Kennedy is from, if you live in Fitchburg or Framingham, Massachusetts, you are 15 times more likely to have your tonsils taken out when you have tonsillitis than if you live in other parts of the state. In some parts of the state, you are several times more likely to have gall bladder operations than in other parts of the state. Throughout this country, there are dramatic differences.

The CHAIRMAN. It is not unrelated to the fact there may be three or four times as many surgeons in those areas where you get the highest degree of procedures.

Senator PELL. In connection with the expense, what is the percentage of health care that one receives in the final year of life? I believe that is almost as much as the rest of your life put together, is it not?

Mr. CALIFANO. I think 30 percent of Medicare funds are spent on people who have less than a year to live.

Senator PELL. Well, is that not perhaps one of the reasons for the difference in cost between the U.S. and other countries where they do not go to such an extreme degree to extend life?

Mr. CALIFANO. Well, I think in most countries a large proportion of the cost is spent on people with less than a year to live. For many of those people, there is no way to know they have less than a year to live as you begin treating them.

I think you are talking about something, the issue of extraordinary care that really requires a cultural change in this country that I sense, at least, anecdotally is beginning to take place. People are beginning to look at hospice care, at dying in the home, at dying with dignity.

There is a wonderful New Yorker cartoon of a man with about 50 tubes coming out of him lying on a table and a woman going into him and saying, "Daddy, how did you ever live to be 190?" It is wonderful. And I think there is an element of that.

But I think our people are changing.

Senator PELL. Well, I think I am correct in saying, for example, that Medicare will take care of bypass but will not take care of a heart transplant. The time will come when heart transplants will be much more accepted, more normal. Then we reach the philosophical question: Should the taxpayer be responsible for procedures that cost a quarter of a million dollars, a half a million dollars?

Do you have any thoughts on that?

Mr. CALIFANO. Well, I think once government decides to get into the business of providing health care, which we did as a nation 22 years ago, government is going to become involved in those issues. We have seen it with the abortion issue. We have seen it with the heart transplant issue. And we will see it with other issues.

I guess I would say I wish Medicare provided more care outside the hospital. I mean, doctors encourage people to be hospitalized because there is no home health care, because there is no real nursing care, because there is nothing less than the most expensive care available for procedures. And a lot could be saved there over time.

Senator PELL. I guess the question I am putting to you is do you think that there should be a dollar limit to health care? Should it be a procedure that costs more than a hundred thousand dollars, for example, would not be permitted? Or do you think there should be open-ended health care?

Mr. CALIFANO. I would not want to put an arbitrary limit on the price that we pay for a procedure and limit procedures to less than that. I think we may come to the point in this country where we have to make some wrenching decisions, but I think there is so much waste still in the system that I would like to get it out of the system, and then see where we go from there and reduce those decisions to the minimum necessary.

Senator PELL. Thank you very much, Mr. Chairman.

Mr. CALIFANO. Senator Kennedy, I would just note that Senator Pell has been my "leader" in taking care of myself, because he runs around the same track in Washington, in Georgetown. He chided me this morning before the hearing because he has not seen me there in the last couple of weeks. So he does take care of his own health.

Senator PELL. And, indirectly, yours.

The CHAIRMAN. Well, on that happy note, Senator Simon.

Senator SIMON. First of all, we welcome you here again. Just two questions.

First, I like your phrase, the minimum health care law. I think it says something that we need to say.

We have this problem already, and that is, let us say, a union enters into a contract with a company for coverage, and then the company hires a lot of part-time people in order to escape some of these costs.

Have you done any reflecting on whether this minimum health care law would cover part-time people as well as full-time?

Mr. CALIFANO. I think it will come in what the definition of full-time people is. I think that you have to look at the numbers. You may want to start to phase it in covering full-time people. I think covering full-time people you will pick up almost two-thirds of those people that are not now covered with health care.

I also think you will have to have rules about which employer's coverage will apply, because we are talking about situations, as these witnesses indicate, where people, just to survive, all members of a family have to work; sometimes they have to work at more than one job.

Senator SIMON. Then a second question. You talked about addiction. You mentioned tobacco several times. I serve on the Budget Committee, and the other day I asked the director of OMB, they do not count user fees as new taxes. And I said what about having a ten-cent tax on cigarettes and having it go to pay some of our Medicaid costs, increase the economic health of this nation \$2.3 billion a year, and particularly discourage young people from getting on

the habit of cigarettes? Every time you increase the cost of cigarettes, teenage consumption goes down fairly dramatically.

Does it make sense from the viewpoint both of our health and our economy to be thinking about something like that?

Mr. CALIFANO. Absolutely, Senator Simon. Let me make two points there. One, independent of health, more than a billion dollars a year in Social Security disability payments are attributable to long-term disabilities from cigarette smoking. It may be two billion by now; it was a billion when I was Secretary of HEW.

And, secondly, we know that increasing the price of cigarettes does result in a decline in the number of teenagers who smoke. And since over 90 percent of the people who are addicted as adults become addicted when they are teenagers, under 20 years of age, it will have a tremendous impact over the long haul on the health of this country. So I think that is a terrific idea.

Senator SIMON. I thank you. Thank you, Mr. Chairman.

The CHAIRMAN. Senator Adams.

Senator ADAMS. Thank you, Mr. Chairman.

Mr. Secretary, I first want to compliment you on your grit and determination. I have seen you struggle with the problem of cost containment for over ten years, and I commend your dedication.

I have just one question. I like your idea of a minimum health care plan. We have a three-legged stool in the United States: one pays, one uses, one provides. Under your proposed plan, how would you coordinate these three elements to ensure that the users, such as those who we have seen testify, are going to receive a level of health care which is not so bare-boned as to expose them?

That is what has always bothered me. We have a Cadillac system that drops out about a third of our people. If we could focus our funding so as to enhance the ability of working families to obtain basic medical protection, then I think most of us would feel we were moving in the right direction.

I would like to know how you would propose to tie those three together.

Mr. CALIFANO. Thank you, Senator.

Let me start by saying one of the best things that has happened to health care policy in this country is that you have been elected to the Senate and you are serving on this Committee.

I think as far as a minimum health care plan would be concerned, you have to start somewhere, and I am suggesting you start with a minimum package of benefits. It would not necessarily cover everything that was discussed here this morning.

I think it is important to keep competition in the system so that we do not escalate prices. That is why I would let the employer choose whatever plan the employer wanted, so long as it provided the basic benefits: a health maintenance organization or preferred provider, some insurance company or—

Senator ADAMS. Would you two tier your competition?

Mr. CALIFANO. Pardon me?

Senator ADAMS. Would you two tier your competition? In our present system, we have a tier of very expensive services that are driving up hospital costs through very exotic procedures. Then we have a whole group of people who cannot access the system at all or, if they access it, are quickly dropped out of it. This affects how

we view our current medical resources. When we say, for instance, that there are too many hospital beds, what we are both really saying is not that there are too many hospital beds for the needs that are out there; but that there are too many hospital beds for the types of services that we are providing.

The Chairman has proposed, and I certainly agree, with a catastrophic protection plan to fill in what you referred to as the "pot-holes." But you are talking about a much more basic minimum care program. These are distinctively different levels of care; the hundred thousand dollar surgery as opposed to seeing that the families basically can get their eyeglasses and prescriptions; and that if somebody has suffered a broken pelvis, that they certainly receive basic care.

Mr. CALIFANO. I see what you are saying. Yes, I think you would have to have, alongside of a minimum health care system, a catastrophic care system. I think one of the points illustrated this morning is in terms of catastrophic care and how it can devastate a family, that it is arbitrary to just say provide catastrophic care only for people that are over 65.

Senator ADAMS. I was just concerned that we might fill in the potholes and forget about the rest of the road. And I just wanted your comments on it.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you very much, Secretary Califano. We will look forward to working with you. I appreciate your presentation here, and we will look forward, as we try and fashion some of these ideas, legislatively, to your continued help and assistance. Thank you very much.

Mr. CALIFANO. Thank you.

The CHAIRMAN. We have one further panel which we will move along to here from now, made up of Dr. Stuart Altman, who is the Deputy Assistant Secretary for Health, Office of Planning under President Nixon; Robert Ball, Commissioner of Social Security, Center for Study of Social Policy; Josh Lederberg, President of Rockefeller University, Nobel Laureate; Sara Rosenbaum, Director of the Child Health Division, Children's Defense Fund; and David Smith, Institute of Medicine Panel for Study on Outreach for Infant Care and Medical Director for Brownsville Community Health Center.

We will move right along. Let us start with Stu Altman. We are glad to have you back before our Committee. Dr. Altman has been before our Health Committee and before the Full Committee on many different occasions. We are glad to have you back.

STATEMENTS OF DR. STUART H. ALTMAN, PROFESSOR, NATIONAL HEALTH POLICY, AND DEAN, FLORENCE HELLER GRADUATE SCHOOL, BRANDEIS UNIVERSITY, WALTHAM, MA; ROBERT M. BALL, COMMISSIONER OF SOCIAL SECURITY (1962-73) CENTER FOR STUDY OF SOCIAL POLICY, WASHINGTON, DC; DR. JOSHUA LEDERBERG, PRESIDENT, ROCKEFELLER UNIVERSITY, NEW YORK, NY; DR. DAVID R. SMITH, IOM PANEL FOR STUDY ON OUTREACH FOR INFANT CARE, AND MEDICAL DIRECTOR, BROWNSVILLE COMMUNITY HEALTH CENTER, BROWNSVILLE, TX; AND SARA ROSENBAUM, DIRECTOR, CHILD HEALTH DIVISION, CHILDREN'S DEFENSE FUND, WASHINGTON, DC

Dr. ALTMAN. Mr. Chairman, thank you very much. It is, indeed, a great pleasure for me to be here before you again. I remembered well the many discussions we had in the mid-1970s about much of the same problems we are discussing today. It is really unfortunate in many ways that the plans you were championing then and we were working on with you were not passed, because the real losers for that failure are the people that we see here today and the millions of other Americans who lack any insurance or whose coverage is so poor.

So if you do not mind, Mr. Chairman, I would like to speak about these problems: a little about what we talked about in the mid 1970s, but recognize that a lot has happened since then and we have learned a lot. Maybe we can use what we did in the mid-'70s but perhaps tailor it more to where we are today in 1987.

As I said, the problem has gotten worse. We have seen more than a 32 percent increase in the number of uninsured since 1978, and millions more whose coverage has been cut back. So much so, that for the first time in 50 years, the percentage of dollars spent by individuals out of pocket is now beginning to turn up. This is the first turn-up in that statistic since 1972.

As you know well, when the Congress failed to act, and the administration as well, during the '70s, much of the activity shifted to the states and the private sector. By and large, they were pretty much caught up with the need to control costs because inflation really hit this sector in a big way in the early 1980s. Private insurance rates were going up 20 percent a year. The Medicaid budgets were the largest of any of the state budgets. So it is not surprising that the major activity was cost containment.

Both of those sectors recognized then, and hopefully will recognize now, that payers need to become prudent purchasers. You cannot just throw the care out there and say, "Buy it." Secretary Califano has indicated all so well how easy it is for us to waste billions and billions of dollars and not receive better health care for anybody.

So we need to become better prudent purchasers, but we also have to recognize in doing that we need to cover these people.

Now, what impact did all this activity have on our health care system? We have seen admissions in hospitals go down for the first time in decades. We have seen length of stay in hospitals decline faster than it has. We really are understanding much better how to control hospital inflation.

It is true that there has been a shift from the hospital to outpatient sites, to physicians' offices and home health, but I think it is a mistake to say that we have not learned how to control inflation a bit.

As we move to these other sectors, new people are getting care, and the care is valuable. So even though our percentage of GNP going to health care has risen again to 10.8 percent, I think we have learned a lot in the last three to five years on how to reduce it. And I think the DRG system has helped. It has caused problems, and we can talk about that. I am not here to be its champion today, but we have learned. It would be a mistake to say we have not.

Now, others have looked to this problem and said, oh, the reason why we have this problem is because of competition, that competition has made health care providers less willing to provide care to the uninsured, our employment-based health insurance system is no good, it ought to be thrown away. I think both would be a big mistake. Yes, both have caused problems. Competition has made it worse. Yes, our employment-based insurance is a problem. But I share Secretary Califano's belief that we need to build on a system that really is in place. We are not Canada and we are not Great Britain.

So what we need to do, I think, is recognize where we are and make it better. I have some suggestions on how we might do that.

First, with respect to cost containment, there is no way we are going to add substantially numbers of new people to the rolls unless we control health costs first. Government can control spending but the problem is that people suffer. And the benefits from government controls are not very obvious. The money goes back to the budget so the savings are amorphous. The people who pay the costs, mainly the patients, who have less access and often feel some of the pinches see none of the benefits.

If you can put the controls on to the private side, the people that bear the costs can see the benefits. We have seen that. When private insurance and private employers cut back, you do see reductions in health insurance premiums; you see more benefits being provided by HMOs when they cut back on hospital; and yes, you also see provider sharing.

And so if I have one strong message I would like to leave you, as you move forward on your proposal: do not wipe out the benefits of competition in the private sector. You need them. Let us build on them, and let us not, if you will forgive me, repeat some of the problems we had in the past.

I think we got caught about those problems and therefore said let us wipe out employer-based insurance, let us wipe out free providers, and as a result we got nothing.

Well, where are these trends going to lead us? I, too, support what Secretary Califano said. I believe that we need to mandate private insurance for all who work. As he pointed out and my statistics indicate, three-quarters of those who are the uninsured are working. And if we can provide them with the coverage, then I think we will have gone far.

This is not the time to outline in detail a proposal, but I would like to put into the record my written testimony and share with

those of you here some of the highlights. In doing that, I would like to recognize that some of the thinking on how to mandate coverage was from work that I did with members of the House Ways and Means Committee and members of your staff in the mid-1970s. So I have drawn a little on that; but I also recognize that 1987 is not 1974, and we need to grow from that period.

Let me just give you a few examples of what we need to do. Several of the Senators indicated that the single greatest problem with mandating coverage is that often the people who need it work for very small firms. These firms are marginal; they do have serious problems. In spite of any kind of pooling, it is quite possible that if you mandate coverage for an individual, it would cost the employer 10 to 15 percent of the person's wage. If you mandate and the person accepts family coverage, it will be 20 to 25 percent. These small employers will find ways of getting around it unless we are very careful. But we still need to move forward.

My suggestion would be that what we do is we grow from this minimum package. Initially, we mandate that every employer has to provide an insurance program that represents at least five percent of their wage bill, and that that should grow over three to five years to seven-and-a-half and then up to maybe ten percent. Yes, in the beginning, Senator Adams, I'm afraid the program may not be as good as we would like. But if we mandate too large a benefit package initially, all we are going to do is find that people will figure out ways to beat it. They will go to hire part-time workers, they will go to contracting out. We will not win.

But we need mandated coverage, and we need to phase it in over time. In 1974, we included a federal subsidy for small employers. I do not think that is appropriate in this day and age. So I would mandate that the percentage of the insurance grow from five percent of payroll at a minimum up to seven-and-a-half and then ten percent.

I believe very strongly, as Secretary Califano, that we should be very flexible with the benefits. I think it is a mistake for us to mandate at the government level too tightly what kind of benefits are included in the mandated plan. Unfortunately, you know what happens. Every provider group comes in; they provide good services. Everybody wants their service to be included in the mandated benefits plan. What starts out as a minimum package very quickly escalates to a maximum. You are up to 15, 20 percent of payroll, and then people do not get it. So we have got to start at the right level. Hopefully, it will be beyond a level that we can live with.

I also would suggest where possible that we use the states as the regulators. They have worked very hard in the last ten years, and quite frankly, many of the states have done a lot better job than the federal government. In Massachusetts, I think we are doing a better job—New York, Florida, California, even Arizona, which when we were talking in 1974 did not have a Medicaid program. People might complain, but Arizona did pass a Title XIX program and it has a lot of very innovative features.

So I would suggest that we do build on the states as the regulators. And similar to Secretary Califano, I do believe we need to wipe out that 20 to 30 percent differential for smaller employer coverage. I think the way to do it is twofold: One, we need to have

a pooling arrangement where states will indicate a limited number of providers, insurance carriers, and those carriers would provide the mandated coverage. But in answer to the Secretary, the second part of the reason why small employers pay more is they pay more for insurance premiums. You do not need that.

Finally, catastrophic. I think we need to build catastrophic coverage into this plan. Again, I do not think we can use a federal subsidy program. My suggestion would be that every insurance company, in every insurance policy a fee would be attached to pay for this coverage. And catastrophic pools would be set up in each area. Then private insurance could go to those catastrophic pools for coverage, say, for expenses exceeding \$10,000 or \$15,000 and get the coverage.

What is critical, though, is you have to build in a managed care system for catastrophic protection. One thing that we have learned in ten years is how to manage high cost care; that is, through a combination of second opinions for surgery, pre-hospital certification, and the funneling of high cost patients to the most efficient providers. We have seen savings of 20 to 30 percent from these activities in the private sector. It does work. Just to put catastrophic coverage out there I think will just break the bank.

So, in summary, Mr. Chairman—

The CHAIRMAN. Do you include the catastrophic in the mandated program?

Dr. ALTMAN. I think so. The people who do not have insurance now are often young, they are often reasonably healthy. But what happens, where they are the most at risk is for catastrophic expenses, not the small items. So I would include it. I think it is a critical component.

In summary, let me reiterate that the problems of the uninsured have grown in the last six years. And I might add when we mandate coverage for the workers, we are not going to solve the problems of the uninsured completely. But it is an important first step, and this is the time to take it.

Again, even though competition has exacerbated some of the problems, it needs to be built on. That is where we are going to get our cost savings. It cannot come totally from regulation. I know. I have been in this regulation business now since 1971. If you do not have the providers and the patients on your side, it is a pretty lonely job to be a regulator and ultimately you lose. So I really believe that you need to build a program which includes patients and providers.

But we do need to build up our financing system. The reason why competition causes the problem is because we are hiding under the rug all of the uninsured. The reason why that rug is so big is because we lack an adequate financing system. So I think we should take the first step and start by providing minimum health insurance coverage for all working Americans.

Thank you.

[The prepared statement of Dr. Altman follows:]

TESTIMONY OF

Stuart W. Altman, Ph.D.

Dean
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BEFORE

COMMITTEE ON LABOR AND HUMAN RESOURCES
U.S. SENATE

January 12, 1967

During each iteration in the search, the fitness function has evolved an approximately linear growth component in the composition of the increasingly heterogeneous population. The most striking observation was indeed that population size. It has remained the vicinity of the population in each iteration in the process with a factor around the value of three. This value could not be high. After all, the size has been approximately constant throughout generations as we proceed with the step-by-step running of the system. Consequently, such a relatively stable value seems more or less normal. But the size and the composition. Between the first and the second iteration, the size of the population has increased by the factor of three, but the size of the population has remained constant. This has happened in the first iteration, but the size has not been constant. At the first iteration, every individual has been constant. At the second

[illegible]

Effectiveness of Surface Interventions in Reducing and Preventing Mortality
D. B. Horsburgh, Jr., *September 12, 1997*

STUART H. ALTMAN, PH.D.
January 12, 1987

Arizona which passed its own version of Medicaid and thereby expanded medical coverage to its low income populations. The Arizona program, however, differed markedly from the original Medicaid design of 1965 and relied on competitive HMO type plans as the major units to provide health services to its indigent population. Similarly, large employers began to stress HMOs as a mechanism to control premium increases which reached levels of 20% per year for two years running. Private insurance carriers, which had been criticized in the early 1970s for failure to be active cost control agents, moved aggressively to develop a variety of alternative delivery system options. Finally, the federal government entered the fray in 1983 with the creation of the Prospective Hospital Payment System for Medicare and an HMO option for Medicare beneficiaries.

Each sector shared the common belief that it was critically important that the ultimate payer for medical services become a more prudent purchaser of care. Second surgical opinions, pre-admission approval and expanded home health coverage as substitutes for expensive hospital services were included in many public and private plans. In addition, most alternative delivery systems established discounting techniques with hospitals and physicians to limit their payment liability. Deductibles and co-insurance were increasingly added to existing fee-for-service insurance.

What impact did all this activity have on our health-care system? Admissions to hospitals which had been rising continually over the last decade, declined for the first time in 1983 and reached a level more than 1.0 million below its high by 1986. Even though sicker people were presumably now being treated in hospitals, the length of the average hospital admission declined more sharply than it had in recent times. More and more medical procedures which had been performed in a hospital were shifted to out-patient sites. While some of these hospital inpatient savings were replaced by growth in outpatient care, the savings in traditionally our most inflationary health sector have been real. In total, hospital spending which increased in "real terms"* between 1979 and 1982 by 3.3 percent per year, dropped to an annual real rate of increase of 1.9 percent between 1983 and 1985. Nevertheless, when increased expenditures for physician services, home health and long-term care are added, total health care spending continues to outpace the productive capacity of the country. As such, the United

*As adjusted by the HCFA/PPS Medical Market Basket.

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States now spends 10.8% of our Gross National Product on health-care services, an increase of 1.2 percentage points since 1980.

What is most unfortunate is that along with these changes in the U.S. health-care delivery system has come a substantial increase in individuals with no health insurance and an even larger increase in workers who witnessed cutbacks in their health insurance coverage. For the first time in 50 years, the percentage of total personal health spending paid by the patient increased in 1984. This percentage had fallen steadily since 1927. It is estimated that the number of Americans with no health insurance increased by 32 percent between 1978 and 1984 reaching a level of 37 million. It has also been reported that roughly one in six New Yorkers lack insurance against the expenses of illness. The increase in the uninsured has come just as many of the traditional sources of their health care are being forced by competitive pressures to cut back on the amount of free care. Tightened governmental payments combined with more prudent purchasing by private insurance has limited the ability of these providers to shift the expenses of the uninsured to others.

Were these two trends coincidental? While all the evidence is not in, it does seem to me that at least some of the reductions in health insurance protection and the increased problems of health providers in treating the uninsured were an "unintended consequence" of the heightened cost containment and competitive environment of the 1980s. Unintended because it was not the intent or the expectation of those that generated these changes that such negative consequences would follow. Competition has been criticized as being responsible for making our uncompensated care problem worse. In a sense this is true because it exposed the extent to which we have been hiding these costs and shifting them to others. But, competition can be an effective technique for making health service providers more cost conscious and efficient. Solving the problem of uncompensated care should fall on the shoulders of our financing system.

Nevertheless, some have suggested that government should restrict the amount of competition as a way of minimizing future growth in the uninsured. Others have pointed to this occurrence as proof that an employment based health insurance system cannot be counted on as the foundation for this country's health care financing system. Both, in my view, are incorrect and would redirect our efforts away from finding a solution to the real critical problem facing our

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health care system -- providing adequate and affordable health insurance protection for all Americans.

THE IMPORTANCE OF COMPETITION AND THE PRIVATE SECTOR

Although the United States did not enact a national health insurance plan or a federal cost containment program in the 1970s, we did learn much about what works and what doesn't work within the context of the US system. There is no question that one of the major impediments to the creation of a national health financing system has been its anticipated costs. In spite of comments to the contrary, it is generally believed that an expansion in the numbers of people covered by a government sponsored third-party payment system will generate increases in health care spending. It is difficult to consider adding more spending to a system that grew by \$175 billion in the decade of the 1970s. Therefore, we must reduce the rate of growth, if not the level of health-care spending before any meaningful expansion of coverage can occur.

Limits in spending can be obtained by governmental regulation, private sector restrictions, or budget controls. Budget controls, which have been effective in other countries, require a degree of governmental responsibility for providing health services which we are not likely to see in this country. Our best bet for limiting health spending, therefore, is to fashion a cost control plan which combines both government regulation and private sector restrictions. Actually, much of the most effective cost control behavior in this country has come through private sector initiatives, primarily through various forms of "managed care." Reductions in hospital days of 20 to 25 percent have been recorded with the aid of second surgical opinions, pre-hospital certification and the channeling of high cost patients to the most appropriate and efficient providers. The pressure for creating these spending control techniques flow from competition among price sensitive insurance carriers and alternative delivery systems.

Governmental cost containment programs at the state level have been effective for limited time periods, but they have also generated long-term problems. These long-term problems, such as the underfunding of new plant and equipment should not necessarily lead to a rejection of such regulations. It depends on the benefits derived from the money saved from these controls. All too often, however, the

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monetary benefits of governmental regulations are obscure, while the problems are very obvious. In contrast, the benefits of privately generated savings are very visible--lower insurance premiums, additional benefits, higher earnings to providers, etc. It is not surprising, therefore, that patients and providers have been more supportive of private control programs than they have of those run by government.

In summary, I would strongly urge that you include as much private sector involvement as you can in any plan developed to alleviate the problems of the uninsured.

MANDATED PRIVATE COVERAGE

Much of the debate of the early 1970s about private versus public administration of health coverage centered on the relative efficiency of each approach. Without clear evidence either way, ideology and self interest took over and the real losers were just those groups of low income working poor who now find themselves with no or inadequate health insurance protection. With the problem even more serious today, I hope we don't repeat the mistakes of the past. We must remember we are not starting from a clean slate. As I said, most Americans receive their health insurance protection from a private carrier and it therefore makes sense to build on our existing system rather than look to a totally new approach. Given that 3/4 of those with no health insurance and an even higher proportion of those with inadequate coverage work, I would suggest you consider mandating that all employers offer at least a minimum package of health insurance coverage to their workers. As I will discuss below, however, you cannot stop there. Health insurance is expensive and by mandating coverage to low wage firms we could jeopardize the jobs of many workers. Techniques must be developed to aid such firms as well as assure that similar coverage is available to an individual if he lacks any employment.

OUTLINE OF A MANDATED HEALTH INSURANCE PLAN

It is not possible in this testimony to present all the details of a federally mandated employment based health insurance system. I will therefore summarize briefly what I consider the major components of the system. In this outline I will incorporate several features of a proposal presented to the Committee on Ways and Means of the U.S. House of

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Representatives in July 1974. The committee plan was developed by Ways and Means staff and representatives from the then Department of Health, Education and Welfare. I was fortunate to be a member of that team. But, 1987 is not 1974 and the solutions of the past need to be modified to account for the many changes that have occurred in the last decade.

Aid to Small Employers:

At the outset it must be recognized that employers will be expected to pay a substantial portion of the mandated coverage premium (60 to 75 percent). For low wage employers, who now provide little or no coverage, mandating a comprehensive benefit package could lead to unacceptably large increases in employee compensation. For example, comprehensive coverage for an individual could require a premium equal to 10% of his wage; family coverage would increase the amount to 20% or more. Some marginal employers could not sustain such increases, others will find ways of restructuring their labor force to avoid such payments. This could lead to the hiring of more part-time workers, the contracting out of services, the substitution of capital for labor, and the more extensive use of a smaller full-time work force.

To combat this problem, the Ways and Means committee proposal called for a 5-year declining federal subsidy for an employer whose premium contribution increased by 3 percent or more. Currently, with the number of workers with no coverage increasing and a greater proportion of the labor force in lower paying service jobs, such a subsidy could lead to a substantial government program. An alternative to a government subsidy could be that the legal mandate be limited for an employer to a premium contribution of 5% initially and up to 7.5% within five years if necessary. Such an approach would lessen the burden on the small marginal employer, but it would also limit the benefits that initially would be in the mandated package to coverage below community norms.

Flexible Mandated Benefits:

In defining the benefits to be included in the mandated coverage, I would suggest as much flexibility as possible. If government attempts to dictate the complete benefit package, every provider group will demand that their service be included. Invariably, the mandated benefit package will grow and could result in serious employment problems. As opposed to the Ways and Means proposal, I would suggest that the federal government not establish its version of an appropriate comprehensive health insurance package. If an

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employer's plan meets some minimum threshold in terms of cost per employee, I would not have government attempt to change it. This legislation should focus on where the major problems are -- employers that provide no insurance or whose coverage is below a truly minimum level.

States as Regulators:

Since states already regulate insurance carriers, I would suggest that they be given the opportunity to oversee the mandate program in their area. Evidence indicates that many of those without coverage today are young and work for a small employer of less than 5 employees. To minimize marketing costs and create a sufficient size pool for experience rating, states could select a limited number of companies in each area. The number should be large enough, however, to permit consumer choice and to offer sufficient variety of alternative delivery system options.

Catastrophic Coverage:

Coverage for catastrophic expenses needs to be a component of any accepted plan. The committee plan called for a catastrophic pool to be created from a special tax on wages and other income. Private insurance carriers could seek compensation from the pool if the expenses for a covered employee exceeded a certain threshold. An alternative approach is to mandate that all health insurance sold pay a fee which would be used to set up such a catastrophic pool in each state. Again, carriers could seek reimbursement from the pool if the expenses for an insured individual exceeded a threshold amount. This would have the effect of creating a reinsurance pool for those with health insurance. The catastrophic pool could also be used by those with no insurance if their billed expenses exceeded the threshold amount. To keep the expenses of these catastrophic pools in line, I would urge the establishment of a high-cost "managed care" system for each pool.

OTHER PROBLEMS REMAIN

Mandatory adequate health insurance coverage for the working population will not eliminate the uninsured. Gaps will still remain primarily among the poor and the aged. To solve these problems Medicaid needs to become a truly national program and Medicare should be expanded to cover long-term care and catastrophic expenses. These are complicated problems and unfortunately will require a major

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addition in government funds. I realize that this is not the year to address these issues, but they should be recognized and work begun to solve them.

In summary, let me reiterate that problems of the uninsured have grown in the last six years and a plan needs to be developed to help them pay their medical bills. Even though these problems are a result of our employment based health insurance system and exacerbated by competition among health providers, our best hope is to build on rather than destroy the employment based insurance system and we should encourage supplier competition. A federal mandate which requires all employers to offer a minimum level of health insurance would be a major first step toward eliminating the problem of the uninsured. More needs to be done, but we should begin today with the first step.

Thank you, Mr. Chairman, for letting me appear before your committee.

The CHAIRMAN. Thank you very much.

If it is agreeable to the Committee, we will go through the whole panel and then come back for questions.

We want to welcome the Commissioner of Social Security and long time friend of this Committee and all of us in the Senate, Bob Ball. Bob, it is nice to have you back.

Mr. BALL. Thank you, Mr. Chairman.

I want to register first that I was very moved by the stories of your first panel. It is true we are the only industrial country in the world that treats low income people who get sick the way we do, we make them choose between no care or begging for charity, and even then sometimes they don't get the care they need.

The time has come when we have to get back to the issue of access. We have been spending our energies on cost control, which is very important; but during that time, as the other witnesses have demonstrated, and I will not go into, coverage and access has gotten worse.

What I want to emphasize is that it is true of Medicare, too. It is true that there are more uninsured among workers than there were. But also the Medicare contraction has resulted in a dimming of the bright promise we had for Medicare when it was passed 22 years ago. The deductible that a person has to pay when he goes into a hospital, which was \$40 when the Medicare program was passed, is now \$520. The copayments in hospital care are correspondingly higher. These increases are vastly more than the increase in the income of the elderly. And, of course, the premium rates have gone from three dollars for the physician part of coverage up to almost eighteen dollars today.

In addition to the fact that older people have to pay more because of these increases in deductibles and coinsurance and premiums, legislative actions since 1980 have increased the costs for beneficiaries. The accumulated changes already enacted, the recommendations of the Reagan Administration that were adopted mean that benefits for the elderly will be cut by \$14 billion over the next five years. The President has proposed cuts in the new budget that, if enacted, would be \$15 billion more.

So the Medicare protection——

The CHAIRMAN. Can we get that straight, because we lose track of that. That is \$14 billion in various recommendations which have been accepted, actually, by the Congress over the period of the last five years. And if these new recommendations are accepted, it is an additional \$15 billion.

Mr. BALL. That is correct, Mr. Chairman, for beneficiaries themselves, not counting lower reimbursement for providers.

The CHAIRMAN. That would be paid for by the Medicare beneficiaries.

Mr. BALL. So, in summary——

The CHAIRMAN. Forget what it would have been if we had not taken the action that we would have taken.

Mr. BALL. Yes. The hospital deductible that I referred to, now \$520, would have automatically been \$578 if it were not for the legislative change that you, Senator, were very instrumental in securing.

To try to summarize the situation: you can say that Medicare now pays less than 50 percent of the total health care costs of the elderly. They are paying as much today as they paid before Medicare.

Now, what can we do? How can this trend be reversed? It seems to me that Secretary Bowen is to be commended, as many witnesses have stated, for bringing to the attention of the country the two big major gaps in Medicare—that is, lack of coverage of catastrophic acute care costs and lack of coverage of long-term care.

But in terms of the specifics, Mr. Chairman, I would think the Congress would want to make rather major changes. The specific proposal is to cover the costs of acute care after people have spent \$2,000. Many, many elderly—I would say half of the elderly, and perhaps more—will have to turn to charity before they reach that \$2,000. In effect, everybody is going to be asked to pay for this coverage if they want any protection against physicians' cost, and almost all the elderly do want this protection. It is a reduction of five dollars a month in all Social Security benefits for the elderly and long term disabled, but the benefits that people get will be largely confined to the relatively well off.

I would think that you might want to change the proposal so that some additional needs would be met before a person reaches the catastrophic cap; a proposal that would cover, for example, prescription drugs under Medicare, and that—in addition to Secretary Bowen's very good recommendation to drop the copayments now required for long hospital stays and lifetime limits would reduce the initial deductible. That \$520 deductible is just a tremendous burden on a large part of the elderly population. You might want to consider making the deductible equal to the cost of a half-day of care in a hospital rather than a full day as at present.

So, in thinking about how to build on the Secretary's plan, I hope you will consider additional types of health care protection that are important to all the elderly, not just those who are relatively well off and would benefit from the \$2,000 cap.

Moreover, I am not particularly enamored of the proposed financing method. If you did change the plan to provide broad additional benefits, perhaps some of the cost could reasonably be met from an additional premium. Such changes in the plan would make a premium increase much more acceptable. But I do not believe all the cost should be met in this way.

The President has made an important proposal in the budget to extend coverage of Medicare to all state and local employees. The three million or so who are not covered under Social Security, a third of all state and local employees, are now frequently getting a free ride under the Medicare program. The President's proposal would bring in \$1.3 billion a year for Medicare. That and other ways of raising earmarked money for Medicare could help meet additional Medicare costs.

Mr. Chairman, the needs of the elderly and the totally disabled under Medicare need to be addressed in these ways, but that is only part of the total problem as other witnesses have testified. I agree, not necessarily with their solutions, but with their identification of the problems.

[The prepared statement of Mr. Ball follows:]

GAPS IN HEALTH CARE INSURANCE
COVERAGE OF THE ELDERLY

By
Robert M. Ball

Presented at a hearing of the Senate Labor
and Human Resources Committee on
Health Goals for the Nation
January 12, 1987

MR. CHAIRMAN AND MEMBERS OF THE COMMITTEE:

My name is Robert Ball. From April 1962 until March 1973 I was Commissioner of Social Security, serving under Presidents Kennedy, Johnson and Nixon. Prior to becoming Commissioner, I served for approximately 20 years in various positions in the Social Security Administration and its predecessor organization, the Social Security Board, and for the 10 years prior to becoming Commissioner I was the top civil servant engaged in the administration of Social Security. I was Commissioner of Social Security at the time of the enactment of Medicare, the establishment of the program as a going operation and was responsible for its administration from 1965 until 1973. Since leaving the government, I have continued my deep interest in Social Security and Medicare and other programs affecting the welfare of the elderly. I was one of Speaker O'Neill's appointees to the National Commission on Social Security Reform which led to the Social Security Amendments of 1983.

I am appearing today entirely on my own, and the views presented in my testimony do not necessarily accord with any of the organizations with which I am associated.

We Need a Health Plan for All Age Groups

I have been asked to speak to the question of the access of elderly people to health care, and I will confine myself largely to that subject, but I do want to make clear at the beginning that the problems this age group has in securing quality care at an affordable price are not unique. Other age groups have as serious or in some instances even more serious problems.

The view is put forward by some that private group health insurance tied to the job is taking care of the financial problem of meeting health care costs for workers and their families and that any residual problem is being taken care of by the Federal-state Medicaid program for low-income people. This is not the case. Group health insurance for workers is widespread, but many in low-paying or part-time jobs or who work for small employers are not covered. And things are getting worse, not better. Between 1978 and 1984 the number of persons without health insurance has increased from 28 million to more than 37 million. Since just about all the elderly have Medicare coverage this growth in the number of uninsured is among those under 65.

In the great recession of 1981-82 when the unemployment rate went up to 10 percent, growth in the uninsured population rose quickly because private health insurance protection is largely dependent on having a job. This is not surprising, but what is surprising is that health insurance coverage has not increased during the recovery. The great majority of those without insurance live in households where there is at least one worker, although, of course, being out of a job continues to be an important cause of being without protection. Under present arrangements,

if we face another recession in the next several years, the number of uninsured could easily rise to 50 million. And we should add to the number of uninsured some 10 million more whose health insurance is woefully inadequate.

The vaunted safety net of the means-tested Medicaid program is full of holes. It is available to less than 50 percent of the population living below the rock-bottom level of officially defined poverty (\$10,989 for a family of four in 1985).

One still might think that even in the absence of health insurance and Medicaid coverage, people in America in one way or another get the care they need--perhaps through public hospitals and the generosity of private physicians. To some extent, yes, and to some extent, no. The differences between the amount of health care actually received by the insured population and the uninsured is very striking and documented in numerous studies. People without insurance tend not to seek care when they need it, and much more often than other people they are denied care for economic reasons.

We are the only industrialized nation in the world that has no system for guaranteeing health care for all. Consequences are unforgivably harsh. For example, many high-risk pregnant women are going without the care they should have and infants are being exposed to permanent damage. We are getting farther from the goal of providing all our citizens with the essentials of adequate care regardless of individual ability to pay, not closer.

For several years now the public policy emphasis has been on cost control. The quest has been for more and more competition and corporate intervention to control costs. And cost control is important. But so is quality care available to all. The public is certainly not content with the present situation. As Dr. Harold Salner, the editor of the prestigious New England Journal of Medicine, wrote in a remarkable editorial in the December 18, 1968 issue of the Journal:

"Polls have always shown a strong public preference for a universal health insurance system over the self-insuring patch-work arrangement we have lived with since the mid-1930s. A recent referendum question in the Commonwealth of Massachusetts asked voters whether the state government should urge the U. S. Congress to start a national health program that would be 'universal in coverage, community controlled, nationally organized, equitably financed, with an out-of-pocket charge . . . and efficient in controlling its cost. . .'. Two-thirds of the voters responded in the affirmative."

He goes on to say:

"Perhaps even the medical profession, disenchanted with the private corporations and the competitive market, will some day be leading the campaign for a publicly financed alternative."

I think it is very likely that such a national health insurance system controlled by national budgets would be a far more cost effective than would the continued growth of our presently unbalanced, largely chaotic combination of private and public insurance, semi-funded programs for the poor and publicly operated hospitals for the low-income population. I believe we should adopt such a system as soon as possible.

These gaps in hospital insurance are quite easily filled. The initial hospital deductible under Medicare ought to be cut in half, and in the future the formula should establish the deductible as equal to the average cost of one-half a day in a hospital instead of a full day, as under present law. The deductible is much too high. It is not desirable to have so much of the cost of hospitalization borne by the sick. But I do not favor removing the hospital deductible entirely. Although patients have little control over whether they enter a hospital or not (it is a physician's decision), some deductible is reasonable as a guard against the admission of borderline cases who could be treated as well on an out-patient basis. Physicians frequently are sensitive to patient costs. There is no good reason, however, to continue with coinsurance for long stays. Under the SHS system, hospitals and physicians have strong incentives to discharge Medicare patients and the additional incentive of copayments is unnecessary and harmful. For the 5 percent or so of Medicare hospital patients who in the course of a year are in the hospital over 60 days the copayments are very burdensome. Requiring a payment of \$100 a day between 61 and 90 days comes just at the time when the beneficiary's resources are likely to be exhausted. And after 90 days, the patient must draw on a lifetime reserve of 60 days and pay a \$100 a day coinsurance. Secretary Bowen's proposal to eliminate these coinsurance payments and the lifetime reserve limit is sound.

The major gap in Medicare coverage, however, now not in hospital insurance, although the problems described should certainly be taken care of. In comparison to the \$1.7 billion the elderly pay out of pocket for hospital care, they pay \$19 billion a year out of pocket for other health services. The big gaps are in Part B physician coverage, and in the

complete exclusion from coverage of certain very important items such as prescription drugs. Another area of great concern that I will address later is the almost total lack of insurance protection against the cost of long-term care for the seriously disabled elderly, whether cared for at home or in nursing homes.

First, let me quickly review the major gaps in acute care under Part B of the Medicare program. Although with a few changes hospital insurance under Medicare can be made to provide fully satisfactory coverage, the same is not true of Part B. Part B is just not very good insurance, and lots of changes are called for. Before any reimbursement is provided, the elderly person has to pay a premium of \$17.90 a month, \$35.80 for a couple, and meet a \$75 annual deduction. The reimbursement is for only 80 percent of an allowable charge. The physician can, and very often does, charge more than the amount on which the Medicare payment is based. Thus in many, many instances the real copayment is not 20 percent of the physician's charge, but 30, 40 or even 50 percent.

This part of Medicare is voluntary and those applying for Social Security can elect out, although well over 95 percent of the elderly covered for hospital insurance and 92 percent of the long-term disabled do take the physician coverage. Inadequate as it is, it is a good buy since 75 percent of the costs are now paid by general revenues.

To try to make up for the inadequacies, 70 percent of the elderly buy supplementary plans from private insurance (another 10 percent are eligible for Medicaid). The so-called Medigap policies of private insurance are very expensive for the protection furnished. A considerable

portion of premium income goes for administration--15 to 35 percent--partly because the individual claims, on average, are small in amount.

By and large the Medigap policies are designed to fill in the deductibles and copayments of Medicare and cover additional days in a hospital or skilled nursing home, using the same definitions as Medicare and not effectively covering the gap between what physicians charge and Medicare will reimburse. They seldom fill the gaps in coverage such as prescription drugs and do not deal at all with the cost of long-term care where the need is primarily for personal services, such as feeding, dressing, toileting, or helping the patient move about.

It is surprising that Part B of Medicare has endured with little basic change for 20 years. It was a last minute add-on in the 1965 Amendments establishing Medicare and was subject to little review at the time. What happened was that the House Ways and Means Committee, after several years of debate, accepted the Kennedy and Johnson Administrations' proposals for hospital insurance based on the traditional social insurance approach of paying the cost while at work through deductions from workers' earnings and matching amounts from employers. But for physicians' services the Committee added a private insurance model sponsored by the ranking Republican on Ways and Means, John Byrnes, that was voluntary, allowed the physician to charge his normal price and was financed in part by a premium paid after retirement. There was a general revenue subsidy of 50 percent of the cost which has now grown to 75 percent.

What can be done to improve Medicare pending the adoption of a national health plan for all? In my view, Secretary Bowen has performed an

important public service in calling nationwide attention to two important gaps in present Medicare coverage: catastrophic protection against acute care costs and the nearly total lack of protection on an insurance basis against the cost of long-term care. I hope that the Congress will use his proposal for catastrophic protection against acute care costs as a beginning point for filling the major gaps in Medicare protection. The Secretary's report on the need for such additional protection is persuasive, and, as he well documented when Chairman of the Advisory Council on Social Security which studied the Medicare program, leaving the solution to an expansion of Medigap policies is inefficient and costly. Medicare, on the other hand, can add protection with the same low-cost administrative mechanisms already in place.*

Important as Secretary Bowen's proposal is, the Congress will, I believe, want to make modifications. A \$2,000 annual cap on covered expenditures is so high that the additional coverage will benefit

*A point about the Medigap policies that is frequently overlooked is that they increase the cost of Medicare substantially and, in effect, benefit from a subsidy from all Medicare payers. That is, they induce additional Medicare costs by removing the constraining effects of the copayment and deductible provisions. Even though the 70 percent of Medicare beneficiaries who have Medigap policies are, on average, younger and in better health than those who do not, they use more care. They are about 1.1 times as likely to be hospitalized, and there is a comparable difference in the use of physicians' services. The additional cost falls most heavily on the 20 percent of Medicare beneficiaries who have such low incomes they cannot afford to buy Medigap policies and at the same time are not covered by Medicaid. This seems inherently unfair.

principally people who are relatively well off. In spite of improvements in recent years in the elderly poverty rate because of Social Security, older people as a group are not well off. Half of all families with one elderly member have incomes below twice the poverty level (\$10,312 for a single elderly person, \$13,006 for a couple in 1985). The median income for families headed by people 65 and over in 1984 was \$13,460. A high proportion of the elderly are going to have to get charity care of one sort or another before they ever reach the \$2,000 proposed cap. It hardly seems fair to impose what amounts to a \$5 a month reduction in everyone's Social Security benefit, including the poor and those with low incomes, in order to provide protection that will be valuable only for those who are relatively well off. That seems to me the clear effect of a \$2,000 cap when the additional cost is paid for by a \$5 a month premium increase.

Perhaps one could improve the Bowen proposal from both ends--benefit structure and the way the protection is paid for. On benefit structure, if one were to add protection that was of major importance to elderly people with average and below average income, such as coverage of prescription drugs, the addition of some health maintenance and disease prevention services, coverage of mental health and substance abuse services and the elimination or considerable reduction in deductibles and coinsurance, there would be a better case for paying at least part of the cost from an additional premium. On the other hand, it is not clear to me why the cost should be met entirely from new premiums. In his new budget, the President has proposed the extension of Medicare to those three million or so state and local employees not currently covered under Social Security (most state and local employees are already covered through voluntary agreements) and this certainly should be done. Under present arrangements, everyone is

paying more for Medicare because this favored group is not included and yet earns full protection by working in jobs covered by Social Security for a relatively small part of their careers. One gets full Medicare protection after a maximum of 10 years of work under Social Security, so while other workers have to pay for Medicare over their whole working careers, these 3 million state and local employees do not. The Congress recognized the injustice of this in the case of Federal employees, and all Federal employees and their employer, the government, now pay toward Medicare protection. This is a good thing for the employees since Medicare becomes the base for any post-retirement health insurance plan and, of course, has the advantage of being portable. Credits earned in just about any job count toward eligibility and state employees who sometimes now work in jobs covered by Social Security for less than the minimum period would be sure to get Medicare protection.

The adoption of the President's proposal would add an estimated \$1.3 billion a year to Medicare, and it seems to me this amount could be used to provide additional protection.

There are other sources of revenue for Medicare. I would favor doubling the tax on tobacco and devoting the proceeds of the entire tobacco tax to the Medicare program. Consideration should be given, too, to raising the alcohol tax and using the proceeds for health purposes. It seems reasonable that those who choose to smoke and drink, and thus increase their risk of having large medical expenses, should pay somewhat more for their health care than others do.

Another possibility is to have well off elderly people pay income taxes on the general revenue subsidy they are getting for their Part B coverage. If we are to continue a policy of subsidizing Part B of Medicare by having 75 percent of the cost paid by general revenues, it seems to me it would be desirable to have the relatively well off elderly at least pay a tax on that subsidy. My long-time associate, Robert J. Myers, former Chief Actuary of the Social Security Administration, has proposed such a tax. Its implementation would be a simple matter of having those elderly who already pay a tax on their Social Security benefits, about 10 percent of the upper-income elderly, also include in taxable income three times the Part B premium--three times because general revenues pays for three times as much of Medicare costs as the premiums do.

I do not completely resist some premium increase for improved benefits if the additional protection is widely distributed. Such an increase is certainly better than having the costs of the program fall to the extent they do today on those who happen to get sick. It is certainly better for all elderly to share in the cost of additional protection than for it to be paid for through copayments and deductibles by those who need health care.

How else can we move ahead?

In my view both parts of Medicare should be combined in a single plan and made compulsory. Physicians' services are as important as hospital care and all the elderly should have that protection too. And to the extent possible, Medicare ought to be expanded to take over the role now being played by the Medigap policies. They are inefficient and costly.

and under present arrangements the confusion for beneficiaries and in administration is almost unbelievable. There is no way for elderly people to follow what is going on when typically they deal with one insurer for hospital care under Medicare, another for physician coverage under Medicare, and another for supplemental plans. Even more important, 20 percent of Medicare beneficiaries have nothing but Medicare coverage. To improve this situation I would hope that the Congress, in addition to combining Parts A and B, would greatly reduce the deductibles and copayments in a new combined plan, and as Secretary Bowen has suggested, eliminate the lifetime limits on hospital days. To the extent premiums, copayments and deductibles are retained, I agree there should be a cap on total expenditures in a year, but the figures of \$1,000 or \$500, instead of \$2,000, would seem to me to be necessary if catastrophic protection is to be a reality for elderly people of average and below-average income.

In time, the expanded plan should be extended to all the disabled receiving Social Security benefits, not just those who have been receiving them for two years as under present law, and all Social Security beneficiaries should be included. Widow and child beneficiaries need the protection as much as older and disabled people. As an intermediate step, it seems to me that it is time to consider health insurance coverage for pregnant women and infants, with the Medicare protection derived either from the earnings of the mother herself or from the earnings of a spouse or parent.

Long-Term Care Insurance

So far I have talked largely about health insurance coverage of the costs of acute care. However, I believe a major emerging issue of the late

1980s will be how to provide protection against the devastating catastrophic costs that the elderly and their families face when there is need for long-term care for patients with chronic illness and disabling conditions, such as strokes and Alzheimer's disease.

The issues surrounding protection against the cost of long-term care must be dealt with in a highly unusual context. People think they already have protection, and they do not. A national survey conducted in 1985 by the American Association of Retired Persons revealed that 79 percent of the population at large and 70 percent of the population over age 65 believed that Medicare would cover a long nursing home stay regardless of the type of care required, and half of those with Medicare and supplemental insurance policies believed that they were covered for long-term care expenditures. This is not the case.

Both Medicare and the private supplements are designed to deal largely with the cost of active treatment and just do not cover the needs of the typical long-term care patient, who by and large does not require the services of a physician or a skilled nurse but rather help in dressing, feeding, toileting, moving from one place to another and in the case of some with mental deterioration, supervision.

Nursing home care, the most expensive part of long-term care, is hardly paid for at all by either Medicare or private insurance (less than 2 percent by Medicare, less than 1 percent by private insurance) and more than half is paid for by the patient or his or her relatives. The rest (44 percent) is paid for by the Federal-state means tested public program, Medicaid.

Most long-term care, however, is not provided in nursing homes nor by professional care givers. Seventy percent of the people with long-term care needs live in private residences and about three-quarters of them receive all needed assistance from family and friends. Another 20 percent receive help from both professional service agencies and family and friends.

The Medicaid program, the only program that is doing much about nursing home expenditures, does not help much on home care. In most states the amount and type of home care provided by Medicaid is extremely limited. Medicaid-covered long-term care is received almost entirely in nursing homes.

To get Medicaid a person must either be poor or be reduced to poverty in the process of trying to pay for care. Few people can sustain independently a stay of a year or so in a nursing home and thus many of those who start out paying their own way end up on Medicaid.

There is much about long-term care that would seem to lend itself to making provision ahead of time through insurance. Any particular individual faces a relatively small probability of needing a large, costly amount of long-term care, but for the few it can be very expensive indeed. A 65 year old faces about a two in five chance of ever needing nursing home care, but for most the nursing home stays are brief. Only a small proportion of the elderly (10 percent) will stay over a year, and this group uses 90 percent of nursing home resources. The average expected nursing home cost for persons who stay for one year or longer is about \$100,000. This kind of distribution of costs would seem ideal for insurance--a large number exposed to a risk but only a small number actually having to pay a large amount.

And individual saving is not an efficient means of meeting the cost of long-term care. If each individual saves to meet a high cost which will be experienced by only a few, the majority have cut back on the use of their money for some other purpose for no good reason. If each individual contributed the relatively small cost of average use, the group as a whole could be insured for quite a low premium. This is what insurance is all about.

Given these circumstances, why hasn't private insurance moved in to meet these needs? There are good reasons. If sold on an individual voluntary basis, there is concern that people will wait until they are quite old and the risk of needing care is high, and indeed, this has proven to be the case for those policies that have been sold. And there is concern that if an attempt is made to cover home care, there will be great difficulty in determining who should get the care, how much and under what circumstances.

There is concern that families now giving informal care will stop doing so if the elderly person is insured for paid care and that the consequent increase in demand could be very heavy.

Because of these concerns, private insurance has not offered much protection. Even now, after years of study it appears that only about 200,000 policies have been sold, with most of these being solely nursing home insurance without the alternative of home care. The policies are on an indemnity basis, a specific dollar amount per day, with coverage limits which preclude payment for extensive stays.

Group insurance which does not have some of the problems of individual voluntary insurance does not seem to be in demand. Employers are greatly concerned about the cost of the supplements to Medicare (mostly acute care) that they are already committed to pay and are more interested in cutting back than expanding. And the unions have not pressed for this type of group coverage.

It is true that several major insurance companies are now active in designing new approaches to long-term care insurance, and undoubtedly some worthwhile protection will be offered, but it is doubtful that widespread private coverage will result. And the proposal to establish another tax expenditure program to encourage those who can to save for the costs of long-term care would not meet the need for the average worker. By now, we know pretty well that it is the relatively well off who take advantage of these IRA type savings plans, and yet all taxpayers bear the cost of foregone revenues.

Given this background, the issues that emerge most importantly are:

(1) Should we undertake long-term care insurance as part of our Social Security system, probably as an addition to Medicare? Spreading the risk to everyone on a compulsory basis and having the payments made by all current workers would make the individual premiums quite low, perhaps in the neighborhood of a half percent of payroll for the employee and a half percent for the employer. And to some extent even this cost would be offset in the national accounts by lower Medicaid expenditures by the Federal and state governments. Today about 41 percent of Medicaid expenditures go to meet the nursing home costs of elderly people.

(2) Is private industry turning from insurance a monopoly to insurance development? Many feel that if a plan were only changing from one that elderly people will be institutionalized immediately and then they will be in their own homes and pay income taxes. But this has been the general, although not exclusive, direction that private insurance has taken.

(3) How can the cost of government plans be kept low and still meet the need? Perhaps by:

(a) Covering only the seriously disabled, not those who need help with two or more of the "activities of daily living."

(b) Requiring a waiting period (say three months of serious disability) before there is reimbursement.

(c) Rationing the home health benefits through organizations that are at risk by reason of being paid a per capita benefit, who work with the elderly person and his family in providing appropriate care and who have the authority to transfer an individual to a nursing home when that is judged less expensive--in other words, the provision of services through a managed care system.

(4) The target would be to design a plan that provides services that does not add to those services by paying the cost and benefit costs of a nursing home and leaving Social Security and private plan costs available. It seems that in this area of insurance a waiting period deductible plus a co-payment for home health care and an open target co-payment when one enters a nursing home (and there is no longer need to maintain a home in the community) might keep the cost at reasonably low level. When all, Social Security and private are supposed to meet nursing home costs, not add to all costs.

The first characteristic of a democratic society is the presence of an organized and effective system of government. This system is based on the principle of the rule of law, which means that the government is subject to the same laws as the citizens. The second characteristic is the presence of a system of checks and balances, which ensures that no one branch of government becomes too powerful. The third characteristic is the presence of a system of free and fair elections, which allows the citizens to choose their representatives.

There are two main types of democratic societies: direct democracy and representative democracy. In direct democracy, the citizens themselves make the laws and decisions. In representative democracy, the citizens elect representatives to make the laws and decisions for them.

There are many advantages to a democratic society. First, it allows the citizens to have a say in the government. Second, it ensures that the government is accountable to the citizens. Third, it promotes the rule of law. Fourth, it encourages the participation of all citizens in the government. Fifth, it promotes the development of a civil society. Sixth, it promotes the development of a free press. Seventh, it promotes the development of a free market. Eighth, it promotes the development of a free and open society. Ninth, it promotes the development of a free and open economy. Tenth, it promotes the development of a free and open world.

The second type of democratic society is representative democracy. In this system, the citizens elect representatives to make the laws and decisions for them. This system is based on the principle of the rule of law, which means that the government is subject to the same laws as the citizens.

Conclusion

We need to move forward to improve health insurance protection for all. Perhaps in a piecemeal fashion this year--wherever it is feasible--but we need to move. We are the only country in the world that spends as much as 11 percent of its gross national product on health care, and we are the only industrialized country in the world that does not guarantee health care for all its citizens. Most disgracefully, we are the only industrialized country in the world that forces many of those with low incomes who get sick either to do without health care or to beg for charity.

The CHAIRMAN. Thank you.

Josh Lederberg, we are delighted to have you back here before our Committee. We have always welcomed your comments. We look forward to them today.

Dr. LEDERBERG. Thank you, Senator Kennedy.

The CHAIRMAN. I want to recognize Senator Harkin who is a new member of our Committee who has joined us now here at the hearing. We are delighted to have Senator Harkin. He has always demonstrated great interest in health care in the past, particularly health care in the rural areas and agricultural communities of this country. He has always been helpful.

Dr. LEDERBERG. I am very privileged to have an opportunity to respond to your leadership and that of your Committee in undertaking a very statesman-like overview of our overall problems in health.

As you have indicated, there are three main pillars that support our health goals: access to care, prevention and research. It is my task to say something about the research part of that.

If you had three or four hours, I would enjoy an opportunity to tell you some of the highlights of the wonderful and exciting advances in medical science over the last decade that really are starting to bear fruit. A lot of were signing promissory notes over the last couple of decades about what the new insights into the biochemistry of the cell and molecular biology were going to do for us. Those promissory notes are being paid off.

Every day in the press we see accounts of new diagnostic or new therapeutic procedures, of new materials coming out of biotechnology, of very exciting new insights about every aspect of human physiology and of human health, I just do not have time to go into that kind of detail at this point.

I would like to say that health research is informed by a sense of strategy. It is not always as clearly articulated as one might like. We have a multi-dimensional matrix of concerns that guide the allocation of resources and the time and attention that individual investigators will be providing for the various kinds of problems.

We have already had some review of the public health challenge, and we have objective statistics on the elements of mortality and morbidity that tell us where some of our priorities are. Heart disease is our major killer, and cancer comes next to that. Those killer diseases do, as they should, occupy a very substantial part of our concern and our research efforts.

We cannot confine ourselves to those killers. There are many other ills that do not have such high mortality, but make life so miserable as to be hardly worth living. The deterioration of joints, body tissues that seem to go along with aging, the deterioration of mental functions, loss of capability, those are things that have to be attended to as well.

We have enormous human misery that comes out of psychiatric and behavioral disorders: schizophrenia, depression of various varieties. We have an epidemic today of anorexia and bulimia, particularly among young women. And we have all the problems of substance abuse that have been mentioned very eloquently before. Those all require close attention to the fundamental knowledge that is needed to find amelioration.

We have problems with the newborn. We have the major anomalies, the major birth defects that are all too prevalent, and we have a universe of ignorance about the very subtle impact of prenatal damage, disease during pregnancy, the effects of malnutrition and of toxins, and even the circumstances of delivery, whether our children are born with all of the potential that they deserve.

Besides the outlook that is given us by the public health challenge, we also have to know about the scientific opportunity. It would be very gratifying if we could respond to these challenges one by one, know exactly what it is that we need to learn and what we need to do in order to respond to each of these conditions. The fact is we are still too ignorant to know how to proceed along those lines.

If we are to pursue the problems of psychiatric disorder, it is not enough to look at the behavior of schizophrenic patients or to try chemicals at random to see which are going to improve their behavior. We have to understand the fundamentals of how the brain is organized, how the neuronal system works, and we are often very much guessing in the dark and playing very long hunches in trying to understand exactly what it is that goes wrong in particular manifestations of disease.

To do all of these things, we need new analytical approaches that can tell us what it is that is going on within the cell, at the boundary of the synapses between nerves and other elements of biochemical analysis.

Then, of course, we have limited resources, limited not only in funds from year to year but in the larger institutional framework in which research is to be done. We have limitations of facilities. We have the need to sustain those institutions that have dedicated themselves to all the problems connected with health. And above all, we have to have those skilled and educated people who need to be trained, motivated and sustained so that they can devote their career to these problems. And those resources cannot be turned on and off with a given year's budget.

And then, finally, we have to recognize that all of this research operates within certain inevitable, necessary constraints. Some diseases are going to be solved much more slowly than otherwise, simply because they are rooted deep within the human organism, and we have limited opportunity of access to them.

Alzheimer's disease is a very tough nut to crack because we simply do not have a way to take biopsies of the human brain at different stages of the development of the disease in order to look closely at what is going on in a given patient. And we do not have an animal model.

When animal models are available, we are under increasing constraints. They come about concern for animal welfare, those concerns that I share. Of course, in order to deal with them, we also have to have the funds to provide the facilities, and those are not always available in the same measure as the complaints about the way in which animals are being dealt with for experimental purposes.

Then I would like to turn to some of the elements of scientific opportunity, and I would like to stress what has become the mainstream of biomedical research in the last several decades, which

happens also to have been the center of my own career: the area of molecular biology. That is perhaps a slightly less formidable phrase than to talk about deoxyribonucleic acid, but I think even that needs a little bit of explanation.

What we have found during that interval is that the basic blueprints of the cell can now be understood in very accurate chemical terms. The chemical involved is the deoxyribonucleic acid, DNA. We have learned the code; we have learned the way in which the messages of the blueprint are stored within the cell, how they are replicated as the cells divide, how they are expressed in instructing the cell to produce various kinds of proteins.

This, in turn, has spawned a new biotechnology, and this is what we are reading about in the papers every day: the production of powerful physiological agents not otherwise available. We have on the market today a pituitary growth hormone, and a tissue plasminogen activator, which is a very exciting approach to dealing with blood clots. We have the interferons and the interleukins which are under trial with various kinds of immunological disorders, virus infections and for cancer, we have new enzymes. And many new vaccines which could not have been feasibly produced by any other means are coming available through the new biotechnology.

We have had something approaching a national emergency in the health field in the last few years with the emergence and alarming spread of the disease AIDS. Five years ago, we were not even sure what it was. In a remarkably short time, with the mobilization of resources that the basic research for preceding decades alone has enabled—we have been able to discover that this is a virus disease, learned a great deal about the nature of that virus, to learn a little bit greatly constrained by fundamental knowledge of exactly how it impairs gene function.

Unfortunately, most of the news we get is bad news, but at least it is accurate in terms of what it is that we have to face as a challenge in dealing with this virus.

Fifteen years ago, had AIDS emerged at that time, we would have been substantially helpless in even comprehending the nature of the challenge. We would not have had the basic tools for laboratory investigation to allow the isolation of the virus, its characterization, what its effect is on various kinds of cells. I know you are having separate hearings on that particular subject, so I will not elaborate.

An important set of the DNA in the cell has to do with the in-borne potentiality within cells to become cancerous. These bits of DNA that are related to cancer are called oncogenes. We have come to recognize that oncogenes can be brought into the cell, can be activated by becoming part of viral agents that can be transmitted from organism to organism. But the more important function of oncogenes in research today is the understanding that they give us of cancers that are not of viral origin but are of endogenous origin, where an oncogene, related bits of DNA, in the normal cell can be activated either by chemical irritants that come from outside or by physiological changes or by radiation, and then take over and result in the non-regulation of these cells where they can become cancerous and a threat to the overall organism.

We have seen the isolation of a couple of dozen of these specialized bits of DNA that provide the potential for cancer. They have really given us our first substantial clue as to what cancer really is. And from the tracing of the pathway from the change of the DNA of ultimate origin of cancer to the nature of the change of the gene products within the cell really is our most substantial hope of trying to find fundamental therapies and a fundamental understanding of what is needed for the prevention of cancer.

If there is one biological concept that has emerged in the last five years, it is the concept of receptors. We have understood that for the cells of the body to be able to function as an organism, to function as a well-regulated society, that they have to have ways of signaling one another, or providing outputs from cells that would determine what the state of the organism was and providing receptors that would be responsive to those inputs.

Receptors used to be a rather vague philosophical concept. They have become very, very material. Receptors are proteins that are responsive to specific chemical signals, that have very definite chemical structure. There are probably dozens, if not hundreds, of different kinds of receptors on different cells of the body, and we are now starting to isolate them. We can actually isolate them as chemical entities only because of the availability of the techniques of molecular biology, the biotechnology mentioned a little while ago.

Receptors have to do with everything in well-ordered bodily functions, whether it is blood pressure or the rate at which cholesterol is taken up, or the growth of cells involved in cancer, or the stimulation of the immune system, or the transmission of the nerve impulse from one cell to another, or the state of activation within the brain, or how viruses infect cells.

The isolation of receptors has probably had the most immediate impact on the way we think about pharmacological intervention and, in a very practical way, in the development of a whole slew of new drugs. Ten years ago, if you had asked me about the realities of new pharmaceutical development, I would have said, well, the future is going to bring about some change, but if you actually look at the list of what is in the Pharmacopoeia, the new entries of that year, they were all produced by hit-and-miss methods, by the very old-fashioned techniques of trial and error.

Just within this last decade, the weight of progress, the advantage has shifted just in the other direction, and every important new drug that has come out in the last five years has come out from an understanding of receptors and looking for specific agents that can either inhibit them or stimulate them.

This applies to the drugs like Cimetidine—

The CHAIRMAN. Can I just on that point, Doctor?

Dr. LEDERBERG. Sir?

The CHAIRMAN. Does that argue for more targeted research or less. If you are getting most of the breakthroughs as a result of just the broadest kind of basic research, does that say anything to whether there ought to be a greater kind of targeting or not? I am just interested in what you think.

Dr. LEDERBERG. Well, we have an opportunity to target that simply did not exist awhile ago. So that if there is a given investi-

gator or pharmaceutical laboratory that wants to go after drugs that are related to lowering blood pressure, well, we have at least some inkling of what systems in the body have to be influenced in order to be able to have that done.

The CHAIRMAN. That has changed significantly, has it not, in the period of the last ten years?

Dr. LEDERBERG. It has changed dramatically in this last decade, and it is working. You do not have to instruct people to target if the opportunity exists to solve a real live problem out there. Our whole system is geared up to try to maximize that opportunity.

The pharmaceutical industry has primary responsibility for that. Its work rests on what comes out of the basic research laboratories, but there really is no problem of knowledge transfer or technology transfer. They are eager to find every opportunity to exploit these kinds of opportunities.

Well, besides these developments in receptors, the notion has emerged that we can now count—what is the fundamental complexity of the human cell? There are three billion units of DNA in every cell of your and my body. If you stretch that out, it would be two meters long. The DNA is so thin and so tightly coiled up that that string of two meters' length, as high as you and I are, gets wound up into a little nucleus that is less than a thousandth of an inch in diameter. But therein is the fundamental information of what it is that allows us to be human.

About 99 percent of that DNA, fortunately for research purposes, is probably essentially inactive, as ballast or some structural material. So the essential component of that total DNA is only about 30 million units long. That will encode for about a hundred thousand different gene products. In order to know the architecture of the human cell, we will have to know about a hundred thousand different building blocks. At the present time, about 300 or perhaps 500 of them have been characterized to some degree. So we have got a long, long way to go in order to fulfill that objective.

It has been suggested that we go after mapping the entire human genome and just get on with it and move from that 500 to that hundred thousand, move from the one million nucleic acid units that have been so far described and get the whole three billion of them and so forth.

As an overall objective, I would subscribe to it. I think we might do better to organize our work so that we focus on those building blocks, on those elements that are the most immediate biological and medical and physiological importance. And then as we do that, we develop improved instrumentation. We can accomplish that task more efficiently, and the end result will be that full map of the entire genome. But some parts of the genome count for much greater importance than others, and I think that is where some of the targeting that you were talking about a moment ago would come in very, very appropriately.

There are many other important innovations in biomedical research. We have all read about the monoclonal antibodies that have given us new reagents of just extraordinary specificity and sensitivity. And these can be used for development of diagnostic procedures that were unthinkable some while ago. The protection of our blood supply depends on immunological reagents designed

along these lines that can detect the AIDS virus. And we are seeing the development of similar reagents for the diagnosis of abnormalities like cancer and like high risk with respect to a variety of other diseases.

I think perhaps this would be a point to conclude with because I could go on almost indefinitely. And I thank you very much.

[Information supplied for the record follows:]

Notes for Presentation to Senate Committee on Labour & Health
 Joshua Lederberg, President, the Rockefeller University, New York
 1/12/87

Three main pillars to health goals:

Access to care; Prevention; Research.

In fact access also needs more analytical research to assure the efficient use of the enormous funds expended. Health care and prevention both look to research for badly needed knowledge for diagnosis, survey, medications and other interventions. In view of limited time, my remarks will be confined to the medical research enterprise.

HEALTH RESEARCH STRATEGIES:

Matrix of

- a) public health challenge, given by statistics
- b) scientific opportunity: where is existing frontier of knowledge.
- c) resources -- funds, facilities, organizations, people
- d) constraints -- ethical and legal regulate pace of much research of human importance

Public Health Challenges

Statistics give us clear guidance about problems!

The principal sources of morbidity and death are listed below.
 However, we cannot overlook the myriad of ills that afflict us,
 especially with aging, even if they are not among the top
 killers - problems of vision, hearing, skin.

Not every challenge is equally amenable to solution
 - need understanding of the scientific opportunity.

In almost every case it is our fundamental knowledge of the
 biology and chemistry of the cell that is the limiting factor.

Killers:

Heart Disease

Cancer

(AIDS as national emergency - subject of other hearings)

Psychiatric disorders

Schizophrenia; depression (constant and biphasic)

Anorexia / bulimia -- epidemic

Substance Abuse

Aging Population

Arthritis; Vertebral syndromes

Alzheimers & other senile dementias

Diminished, altered immune response

Birth Defects

major anomalies

subtle impairments

Third World Disease is neglected

How it gets back to US!

AIDS should teach us that lesson

Parasitic Disease

Diarrheal disease: cholera and treatment of pediatric US

RESEARCH OPPORTUNITIES :: EXCITEMENT OF LAST DECADE.

{I will mainly elaborate on these, as reflecting my own specialized interests. Research Briefing Papers of the Institute of Medicine offer more detail on many.}

Most advances came without any way to foresee what the detailed application to disease would be

Molecular Biology

Last 40 years — spanning my own career in science — have been of the greatest excitement. The substance DNA is found to embody the blueprints of the cell. We can deal with DNA in material terms, diagnose its detailed structure in health and disease, move sections of DNA from cell to cell.

This has also spawned the new biotechnology, enabling the production of powerful physiological agents not otherwise available (e.g. pituitary growth hormone, TPA (for blood clots), interferons, interleukins, many enzymes, etc.) as well as new vaccines.

Whatever headway has been made in understanding AIDS virus in the last few years has come entirely from molecular biology.

Gene therapy (misnomer) also proposed, to "fix" defective body cells — not hereditary traits in germline!

Most important, however, is not those technologies, but the understanding we can get of how the cell works.

Mapping the Human Genome - how DNA works and is regulated
There are about 3 billion "nucleotide" units in the DNA of every human cell. Proposal for systematic project to map the totality. We should get there, and need new technology, but in my view better by problem-focussed research than by brute force. E.G. one investigator will want to type all the DNA that has to do with the development of the retina, another with susceptibility to virus infection, and so on. However, some systematic mapping is a good idea — like getting the baseline maps of the geodetic survey, but more selective approach before we drill deep holes in every square inch.

Oncogenes are an important subset of these genes. Found in normal cells, but also in cancer-causing viruses in animals, and in altered form in cancer cells. Our best clue to what cancer is, and how it is caused. About two dozen different oncogenes now known, just being sorted out what they do. Already being used for diagnosis; help us understand hereditary cancer, with inborn propensity for cancer (retinoblastoma). Some genes suppress cancer; cancer develops when those genes are damaged. Helps explain why same kinds of chemicals and radiation cause hereditary mutations and cancer.

Concept of "receptors" -- important new organizing concept.

Cells need to exchange signals with each other and with the immediate environment. Cell surfaces have specific signal-receivers or receptors. applications to everything from

heart disease: how cells recognize cholesterol and take it up from blood

cancer: signals control pace of growth of cells

immunology: activation of lymphoid cells to make antibody
derangements in auto-immune disease, AIDS, other infections

brain: how one nerve cell signals another, it puts out a chemical signal that binds to the receptor (across the synapse) of the next cell. Problems arise when receptors are overstimulated (schizophrenia; mania) or under (depression) in specific parts of brain.

virus infection - how viruses attach to cell surfaces, then penetrate and harm them

Monoclonal antibody; cellular immunology

Exquisitely specific reagents for diagnosis and treatment.

acquired by culturing (cloning) single cells of immune system involved in making one specific antibody. Then trick of fusing these with a cancer cell line that makes them grow and work overtime in making antibody.

Blood supply can now be protected from AIDS

Exploration of auto-immune diseases (arthritis?); Multiple sclerosis?

Computer science

Diagnostic Imaging: CAT scanners; Magnetic Resonance Imaging which avoids excess radiation exposure in diagnosis.

Spillover: Research on Artificial Intelligence in Medicine, originally directed at the development of diagnostic assistance in medicine, led to the development of expert systems, which are the leading edge software for industrial application today.

Neurobiology

Organization of the brain

How the nerve impulse works; chemistry of neurotransmitters and application to new medications for psychiatric disorder and blocking agents for treatment of drug abuse.

MEANS OF RESEARCH AND TRANSFER INTO PRACTICE.

facilities

people

maintaining integrated perspective

e.g. clinical research

institutional performers taken for granted

need for investment outlook - people not projects

capital needs; overhead issues

(Detailed discussion in White House Science Council Report
on Health of Universities)

private sector

main avenue of technology transfer

three sectors working better than ever

international competitiveness in biotech

medical education

equally important avenue of tech-transfer

research setting not excessively driven by project performance

but by quality of mind and effort indispensable

how attract gifted, dedicated people into medicine and medical

research? Offer stability of opportunity, confidence of

pursuing long shots, that years of arduous training will be

rewarded with confidence in their own judgment.

(Editor's Note: Due to printing limitations and in the interest of economy, certain additional supportive material supplied by Mr. Lederberg consisting of an article entitled "Cycles and Fashions in Biomedical Research", and reports of the Research Briefing Panel on neuroscience, viral diseases, protein structure, immunology, atherosclerosis, oncogenes, parasitism, and pain, was retained in the files of the committee.)

The CHAIRMAN. I wish I had spent more time paying attention in science in school in listening to your excellent presentation of all these matters.

We are going to move to a somewhat different phase of our better understanding about what is happening across the country in health care with our final two witnesses. We want to give you assurances that your messages are going to be listened to with great interest by me, and I know it is a very, very important one.

First, we will hear from David Smith, and then I will ask Sara Rosenbaum if she will wrap up the morning for us. We have gone through and talked about a three-legged stool, and we have listened to a very eloquent presentation about the possibilities and the changes that have taken place in the biomedical area as well as access. I think we will hear more about access and the typical availability of health care in both urban and rural areas. We will first hear from David Smith and then we will ask Sara Rosenbaum to speak to us, I know very eloquently, as she has to other committees about the challenges for children in health. This is something which I know David Smith is interested in and I think all of us as a country must be. We will start off with David Smith. Glad to have you here.

Dr. SMITH. Thank you, Mr. Chairman. I am very honored to sit on this distinguished panel—I wonder if perhaps I belong—and certainly to make some comments before this Committee.

I would like to begin as qualifying my position. I am really here as a pediatrician as much as anything to represent what I believe are my constituents, my patients in Brownsville, Texas. I think I need to qualify that a little bit about where I am and where I am coming from.

Brownsville, of course, brings connotations of one river, one country, and often; the term "occupied Mexico", particularly in some legislative bodies in Texas. But I think that we must realize that—

Well, we are already an occupied territory in Brownsville, according to Doonesbury.

I might mention, though, that in fact our greatest problem is not illegal aliens. I am the medical director of a large migrant and community health center. We have about 25,000 patients in our health center which represents about a quarter of the population of Brownsville.

Less than three percent of our total population of patients are illegal aliens, and most of those are transient visits. In fact, a lot of them are patients that saw advertisements in local Mexican newspapers for hospitals in the United States and were refused care at the hospitals and ended up at our doorstep.

I might, as an introduction to health care in Brownsville (in Cameron County), invite Senator Kennedy and anyone else that would wish to be a midwife or lay "partera" to come down to Brownsville. For \$5 anyone in this room could be delivering babies tonight. It is part of the frustration of health care delivery in Brownsville. Its U.S. citizens and residents require this service because they cannot access other terms of health care. I reiterate it is not a major problem as far as illegal aliens. The entire county's de-

liveries of non-residents is less than 12 percent. A number of those are residents of surrounding counties.

It is very impoverished area of the country. The last time I looked, it was about the third poorest county in the United States. I believe the next two poorest are in the two surrounding counties.

We also serve about half the school children of Brownsville. Of 33,000 school children, we see about 15,000 of those children in our clinic.

I am here to speak about the maternal and child aspects of this health care and some of the problems that we have been forced to deal with in this setting. For me, it was a very rude awakening because I came from one of the most expensive hospitals in the United States, Children's Hospital in Philadelphia, participated in research, pediatric research. But then to come to Brownsville and see that, Third World conditions exist within the United States is quite a shock.

The thing that I think is particularly frightening, and relevant is that the local situation is applicable to the entire country. I recently did a survey of health centers, migrant and community health centers, which I might add many Committee members have been involved in the legislative process for this group. I believe the centers do a wonderful job. They provide not only education in prevention care and also provide maintenance care. As an aspect of this care we do have to admit patients from time to time.

This particular survey surveyed primarily migrant health centers in this country, but many of these now are combined, seeing both migrants and what we classify as community health patients under the Health Services Act. Most of these centers are primarily federally funded.

This particular survey identified some significant barriers in health care access. One of them which came to the forefront quite readily was the process or the request for pre-admission deposits, and I have included with my written testimony copies of some of these. I would like to discuss this particular problem as a barrier.

As I made the point within the written testimony, in some cases these pre-admission deposits exceed \$3,500. I might add that the annual per capita income in my county in 1980, before the peso devaluation and before the citrus freeze, was \$4,600 a year.

The individuals that are described within this health care setting are unable to pay this particular amount of money. I coined a phrase that I have used quite frequently called the "fear factor." We have discussed it here today. I have heard it several times. The term "fear" has been used by, in fact, all three sets of panelists.

It is when an individual goes in, and I call it also the Sears television purchasing philosophy of trying to walk into a hospital for care, and the social worker states, "Well, you would not think of walking out of Sears with a television without paying for it. Or you would not walk into a grocery store and take a bag of groceries out without paying for it. How dare you come into our hospital and expect care."

Well, for many of my patients, constituents, that is enough to send them elsewhere. And, of course, that is why lay midwives, all 60 of them, proliferate within our area. In fact, our county ac-

counts for ten percent of the nation's total out-of-hospital deliveries by the last count.

Let us discuss a couple cases and what happens to gainfully employed individuals within our setting. One particular case is a case of an Angie Picasso. She was a pregnant woman, Hispanic U.S. citizen who required a cesarean section. She had had a previous child by cesarean section and had been followed by our physicians in the health center. Her husband was employed by an electric company in Brownsville and made about \$11,800 a year and they had one other child. They did not qualify for any sort of state assistance or federal assistance programs. They owned a small shack that had an electric cord running from their neighbor's to provide electricity, and they did not have a telephone.

The Picassos came to us because they needed assistance. They could not afford the hospital care, did not have health insurance under the plan of the employer, the electric company. And our only alternative was to try to get them into some other hospital for the needed cesarean section. What we were able to do after a rather lengthy process that, in fact, took myself and my obstetrician almost two days to complete—while I should have been seeing patients, as I do five days a week—was to get the patient into Galveston. For most of us, you think of Texas as large, and I never quite understood how large. Galveston is almost 400 miles away from Brownsville, certainly not an acute care setting or something that we can utilize as an emergency hospital.

But this is all that we could do at the time because she could not pay the \$3,500 deposit requested, and I will enter into the testimony and statement a copy of, in fact, her deposit request. It is not in the packet that you received.

The story becomes more complex. The father asked for a request to leave work so that he could go with his wife to Galveston. They arrived at Galveston, were examined, and told that the mother should wait a couple days, go back to Brownsville and come back because she was not quite ready.

She returned to Brownsville, and several things happened, not the least of which is that she went into labor, which was something you generally do not like to have happen to a cesarean section patient. But, in addition, the father came back to find out that the verbal agreement for his job to be waiting had been ignored and he was without work.

In addition, the money to pay for room and board in Galveston, we have provided assistance for the plane flight, had been pulled out of his deposit for his apartment. He returned to find that his apartment no longer existed. His job was not any longer in the offing, and so he was unemployed. The irony of this is that this man now qualified for Medicaid. And so, indeed, the same hospital that refused him for the \$3,500 deposit was now going to deliver them with our physician doing the cesarean section.

Well, at least, there is a "happy ending" to this particular story. This is not the case of another instance where a woman by the name of Mrs. Alvarado had a similar set of circumstances. She was a U.S. citizen living in a similar "colonia." Colonia are clusters of crude shacks made often of plywood. She had three other children. She attempted to preregister at the hospital and could not come up

with the deposit. Her husband did odd jobs and made about \$5,800 a year. In addition, they had a car because they occasionally migrated as migrant farm workers.

They did not qualify or could not pay for the \$3,500 deposit that the hospital requested, and they came to us for assistance. We attempted to get them into Galveston. The beds were full and we were not able to accomplish that.

She elected to go to a lay midwife. She had a large baby, was hypertensive, and had high blood pressure. She was a diabetic and very obese and also 37 years old, so by definition placed in a very high-risk category for delivering with a partera, or with Senator Kennedy if he chooses to go down there to work.

She went there knowing these difficulties and delivered a child, or at least the head of a child, in the partera's residence. The partera, because of the size of the child, could not deliver the rest of the body. And, in fact, after about 20 to 30 minutes, the partera told her there was no way that this baby was going to be delivered and survive.

Mrs. Alvarado, unlike most of us who would want to go immediately somewhere for help, insisted that the partera get the baby out any way she could because she could not afford to go to the hospital. She had previously owed them \$1,000 for a similar problem with a delivery several years before.

The partera was unsuccessful in getting the baby out, and, indeed, this child came back with the mother in a taxi, partially delivered, and delivered with our obstetrician. The child was delivered dead. This is preventable morbidity and mortality. There is just no reason for this to happen. I do not need a CT scanner, I do not need an NMR. I certainly do not need to be dealing with the research issues of rota virus. I just need the hospital bed and the ability to provide some primary care and preventive hospitalization.

It is often brought up that these folks do not help themselves. Well, I might bring out the other point that I have another access problem. Despite the feelings of my community, I have 500 women who wish tubal ligation. I cannot even access them into a system of formal family planning because of lack of funding in the area. These women desire this, know they cannot afford to have more children, are involved actively in our family planning program, but we cannot give them what they really need because of lack of funding.

I think that this story is illustrative as far as the particular problems that we have. I think that I need to turn just a minute to the effectiveness of prenatal care and outreach, something I am involved in actively with the Institute of Medicine under the National Academy of Sciences.

Certainly, preventive health care is cost effective, and it appears that for every dollar spent there is at least a three to four dollar savings, and some people feel even greater. I believe that you must tie preventive health care or outreach to patients with access to needed care. You cannot offer prenatal care or an outreach and then not be able to deliver the individual. You will soon find that the information disseminates through the community, and no one

will come to you for health care because you cannot deliver them or care through with a treatment regimen.

Indeed, that is one of the interests of the Institute of Medicine, and it has been something that we have been toying with because it is very nice to sit and deal with the issue of outreach and preventive health care, but when you cannot deliver the goods, so to speak, you are in trouble. In fact, your program will be ineffective.

That brings me to another issue that has been discussed today, and that is the catastrophic insurance. Catastrophic insurance, is in its concept a good program. I think we are going to need that, and it needs to be tied with other mandated programs. But it looks at the other end of the tunnel. It does not attempt to narrow entry into the system. In other words, preventive care, outreach do that. Improving access to those who are identified and controlled quality systems of delivery or health care prevent the number that will ultimately need catastrophic insurance.

Overall the amount of money spent on health care is probably sufficient. It is mismanaged, and physicians are partly to blame. I think that is another area we need to look at. As a physician, I am willing to do the fingerpointing. We do need to review critically what we do, and ask the questions how often, when, and for how much?

My concern, as I summarize, is that, this nationwide study that I conducted demonstrated clearly numerous barriers to health care and access exist. We need to address these. In addition, I am afraid that with such things as pre-admission deposits and differentiation of care that is outlined within my study, we do put a price tag on human life. I think that a \$3,500 pre-admission deposit is nothing more than that. I am sorry, but I did not learn the price of a human life when I went to medical school, and I still have not found what that value is.

I would close on those remarks. Thank you.

[The prepared statement of Dr. Smith follows:]

TESTIMONY BEFORE THE SENATE COMMITTEE ON

COMMERCE AND HUMAN RESOURCES

JANUARY 12, 1987

DAVID SMITH, M.D., F.A.A.P., MEDICAL DIRECTOR

BROWNSVILLE COMMUNITY HEALTH CENTER

HEALTH CARE IN THE UNITED STATES NOW CONSUMES APPROXIMATELY 400 BILLION DOLLARS A YEAR,¹ OR ABOUT \$1,700.00 FOR EVERY INDIVIDUAL IN THIS COUNTRY. YET THIS EXPENDITURE, DESPITE EXCEEDING THE TOTAL YEARLY DEFENSE BUDGET, IS DISPROPORTIONATE, AND 35 MILLION PEOPLE ARE WITHOUT HEALTH INSURANCE² GROPING FOR A MEANS TO DEAL WITH THE SPIRALING COSTS OF HEALTH CARE. WHETHER YOU BELIEVE HEALTH CARE IS A RIGHT OR PRIVILEGE, INDIVIDUALS (HUMAN BEINGS, ONE THIRD OF WHICH ARE CHILDREN) ARE BEING PRICED OUT OF THE HEALTH CARE MARKET. THIS NATION HAS WHETHER CONSCIOUSLY OR UNCONSCIOUSLY PLACED A PRICE TAG ON HUMAN LIFE. THIS IS REFLECTED IN THE FLOURISHING OF \$3,000.00 PRE-ADMISSION DEPOSITS NOW BEING REQUESTED IN MANY HOSPITALS. IN A RECENT NATION-WIDE SURVEY OF MIGRANT AND COMMUNITY HEALTH CENTERS 59% OF THE HOSPITALS IDENTIFIED REQUIRED A PRE-ADMISSION DEPOSIT.³

SEVERAL ADDITIONAL ISSUES HAVE "SURFACED" NATIONALLY AND HAVE RESULTED IN FURTHER BARRIERS BEING CREATED IN THE QUEST FOR HEALTH CARE. IN ADDITION TO THE UNINSURED, IT IS ESTIMATED THAT 56 MILLION AMERICANS ARE UNDERINSURED, AND HAVE INADEQUATE COVERAGE.⁴ IN A REPORT PUBLISHED BY THE ROBERT WOOD JOHNSON FOUNDATION IN 1983, ACCESS TO HEALTH CARE WAS COMPROMISED FOR ABOUT HALF OF THESE INDIVIDUALS.⁵ THE STEREOTYPE OF THE INDIVIDUAL "MILKING THE SYSTEM" APPEARS TO BE IN ERROR, AS A STUDY BY THE AMERICAN HOSPITAL ASSOCIATION REPORTED, 65% OF THE UNINSURED ARE EITHER WORKING OR DEPENDENTS OF EMPLOYED FAMILY MEMBERS.⁶ MEDICAID HAS INCREASINGLY BECOME A RE-INSURANCE PROGRAM FOR MEDICARE.⁷ DESPITE REPRESENTING ONLY 35% OF THE TOTAL MEDICAID POPULATION IN 1975, MEDICARE ACCOUNTED FOR 65% OF THE TOTAL

MEDICAID EXPENDITURES.⁸ ADDITIONAL STATE AND FEDERAL CUTBACKS OVER THE LAST 5 YEARS HAS INSURED THAT MEDICAID COVERS LESS THAN 40% OF AMERICANS LIVING BELOW POVERTY.⁸ SOME STATES HAVE PASSED INDIVIDUAL INDIGENT HEALTH CARE LEGISLATION, HOWEVER LOW RATES OF REIMBURSEMENT AND FAILURE OF PARTICIPATION BY MAJOR FOR-PROFIT AND NON-PROFIT HOSPITALS IN SUCH STATES AS TEXAS HAVE LEFT HUNDREDS OF THOUSANDS OF DOLLARS UNSPENT, AND INDIGENT PATIENTS WITHOUT HEALTH CARE ALTERNATIVES. PREGNANT WOMEN WITH MULTIPLE COMPLICATIONS HAVE BEEN "TURNED AWAY" AFTER BEING UNABLE TO PAY A \$3,500.00 DEPOSIT, AND "FEARING" THE DEBT THAT WOULD BE INCURRED IN A FAMILY OF FOUR AND A COMBINED INCOME OF \$5,800.00 PER YEAR (THE FEAR FACTOR).⁹

MALPRACTICE, NOTED FOR ITS ABILITY TO APPEAR IN FRONT PAGE BY-LINES, IS A HIGHLY CHARGED EMOTIONAL ISSUE. THE MALPRACTICE HEARINGS ON CAPITOL HILL HAVE ALLOWED MANY "SPECIAL INTEREST GROUPS" TO EXERCISE THEIR EXTENSOR INDICIS MUSCLE (INDEX FINGER) IN ATTEMPTS TO IDENTIFY THE GUILTY CULPRIT. INDIVIDUAL SERVICES FOR THE POOR HAVE BEEN TERMINATED AS A RESULT OF THE MALPRACTICE CRISIS, AND "DIRECTLY OR INDIRECTLY RESULTED IN PREVENTABLE MORBIDITY AND MORTALITY"⁹ THE CLOSING OF MATERNITY CENTERS UNABLE TO PURCHASE MALPRACTICE AND LIABILITY INSURANCE HAVE RESULTED IN INDIGENT WOMEN LEFT WITHOUT AN ALTERNATIVE FOR CARE AND IN SOUTH TEXAS CONTRIBUTED TO THE DEATH OF TWO INFANTS.⁹

PREVENTIVE HEALTH CARE IS COST EFFECTIVE, AND REQUIRES CASE IDENTIFICATION. OUTREACH IS AN INTEGRAL COMPONENT OF THIS ASPECT OF HEALTH CARE, PARTICULARLY AS RELATED TO EFFORTS IN CASEFINDING, FOLLOW-UP, SOCIAL SERVICES SUPPORT, AND INTEGRATION INTO EXISTING

PROGRAMS. HOWEVER, OUTREACH IS OFTEN NOT A FORM OF REIMBURSEABLE CARE, AND MAY BE ONE OF THE FIRST ASPECTS OF PREVENTIVE CARE TO BE ELIMINATED. THE EFFECTIVENESS AND BARRIERS TO ADEQUATE OUTREACH PROGRAMS IS CURRENTLY THE TOPIC OF A NATIONAL ACADEMY OF SCIENCES COMMITTEE.

DESPITE THE EFFECTIVENESS OF PREVENTIVE CARE, AND PATIENT EDUCATION, TIMELY HOSPITAL ADMISSIONS ARE AN INTEGRAL PART OF GOOD PATIENT CARE. IN A RECENT SURVEY OF FEDERALLY FUNDED MIGRANT AND COMMUNITY HEALTH CENTERS SIGNIFICANT BARRIERS TO HOSPITALS ACCESS WERE IDENTIFIED. THESE CENTERS TENDED TO AVOID THE FOR-PROFIT INSTITUTIONS OF WHICH 80% REQUIRED PRE-ADMISSION DEPOSITS, AND 40% DENIED ACCESS TO THE INDIGENT REQUIRING HOSPITALIZATION.³

THE DIFFICULTIES IN GAINING ACCESS TO HOSPITAL CARE ARE PARTICULARLY APPARENT IN SOUTH TEXAS. THE BROWNSVILLE COMMUNITY HEALTH CENTER PROVIDES AN APERTURE WITH WHICH TO VIEW THE FRUSTRATIONS OF THIS ISSUE. THE HEALTH CENTER IS A LARGE MIGRANT AND COMMUNITY HEALTH CENTER LOCATED IN SOUTHERN CAMERON COUNTY, ONE OF THE POOREST COUNTIES IN THE NATION. THE CENTER CURRENTLY HAS A REGISTERED PATIENT POPULATION OF OVER 25,000 INDIVIDUALS, OVER 80% AT OR BELOW 100% OF THE FEDERAL POVERTY LEVEL. THE AVERAGE PER CAPITA INCOME ACCORDING TO THE 1980 CENSUS WAS \$4,600.00, AND WAS CALCULATED PRIOR TO THE PESO DEVALUATION. DESPITE BEING A "BORDER TOWN" LESS THAN 3% OF THE PATIENT VISITS ARE ATTRIBUTED TO "UNDOCUMENTED ALIENS". THE HEALTH CENTER PROVIDES HEALTH CARE TO APPROXIMATELY $\frac{1}{2}$ OF ALL THE SCHOOL CHILDREN IN BROWNSVILLE (14-15,000), AND $\frac{1}{4}$ (25,000) OF THE ENTIRE POPULATION.

THE TOTAL NUMBER OF BIRTHS IN CAMERON COUNTY IN 1985 WAS JUST OVER 6,200; 41%, OR 2400 WERE OUT OF HOSPITAL DELIVERIES. THE MAJORITY OF THESE BIRTHS ARE PERFORMED BY LAYMIDWIVES OR "PARTERAS", WHO HAVE NO FORMAL TRAINING. THE ONLY REQUIREMENT TO BE A PARTERA IS TO PAY A \$5.00 REGISTRATION FEE AT THE COUNTY CLERK'S OFFICE. SIGNIFICANTLY, THE OUT OF HOSPITAL DELIVERY RATE REPRESENTS ALMOST 10% OF THE NATION'S TOTAL OUT OF HOSPITAL DELIVERY RATE. THIS ISSUE, ALONG WITH THE FACT THAT THE LOWER RIO GRANDE VALLEY HAS ONE OF THE YOUNGEST POPULATIONS IN THE NATION, AND ONE OF THE HIGHEST FERTILITY RATES, ESTABLISHES THIS AREA AS A POPULATION AT RISK. TEENAGE PREGNANCY OCCURS AT A RATE OF OVER 1 IN EVERY 20 FEMALES IN THE SCHOOL DISTRICT OF CHILDBEARING AGE.

THE SITUATION IS FURTHER EXACERBATED BY THE RIGID STATE FINANCIAL REQUIREMENTS FOR MEDICAID, WHICH ONLY REACHES ABOUT 26% OF THE POOR, WHILE THE NATIONAL AVERAGE IS OVER 40%.¹⁰ THE "NEW" INDIGENT HEALTH CARE LEGISLATION ADOPTED IN 1985 HAS YET TO BE FULLY IMPLEMENTED, AND MANY FOR-PROFIT AND NON-PROFIT HOSPITALS HAVE ELECTED NOT TO PARTICIPATE IN THE HOSPITALIZATION PAYMENT PROGRAM UNDER THE MATERNAL INFANT HEALTH IMPROVEMENT ACT (MIHIA) ASPECT OF LAW. THE HEALTH CENTER IN BROWNSVILLE HAS BEEN AWARDED \$260,000.00, BUT HAS BEEN UNABLE TO USE THE MONEY TO ACCESS THE INDIGENT, AS NEITHER HOSPITAL IN BROWNSVILLE HAS AGREED TO PARTICIPATE WITH THE CENTER. INDIGENT WOMEN HAVE BEEN FORCED EVEN IN HIGH RISK SITUATIONS TO DELIVER WITH LAYMIDWIVES, AND UNFORTUNATELY PREVENTABLE MORBIDITY AND MORTALITY HAS OCCURRED. BOTH BROWNSVILLE HOSPITALS ARE FOR-PROFIT, AND ROUTINELY REQUEST PRE-ADMISSION DEPOSITS (SEE ENCLOSURES) OF UP TO \$3,500.00.

THESE DEPOSITS HAVE EVEN BEEN REQUESTED IN EMERGENCY SITUATIONS IN VIOLATION OF MEDICARE/MEDICAID LEGISLATION PRIOR TO THE INITIATION OF SERVICES. ONE PARTICULAR PATIENT MRS. ALVARADO, 9 MONTHS PREGNANT WITH THE INFANT COMING OUT FEET FIRST AND REQUIRING A CESAREAN SECTION, LEFT THE HOSPITAL BECAUSE SHE DID NOT WANT TO INCUR THE DEBT WHICH WAS VIVIDLY DEPICTED BY THE HOSPITAL SOCIAL WORKER. MRS. ALVARADO ARRIVED INITIALLY AT THE HOSPITAL FROM THE HEALTH CENTER IN AN AMBULANCE, INTRAVENOUS IN PLACE, AND LEFT AFTER THE DISCUSSION WITH THE SOCIAL WORKER WITHOUT THE PHYSICIAN BEING NOTIFIED. THE PHYSICIAN WAS AWAITING THE PATIENT'S ARRIVAL IN THE OPERATING ROOM. THE HOSPITAL SITUATION CAN BE PLACED IN PROPER PERSPECTIVE WITH THE REALIZATION THAT THERE IS NO STATE OR COUNTY HOSPITAL FACILITY, AND THE NEAREST REFERRAL HOSPITAL IN GALVESTON ALMOST 400 MILES AWAY.

THE HEALTH CENTER CURRENTLY DELIVERS APPROXIMATELY 900 WOMEN A YEAR, IN ADDITION TO PROVIDING PRENATAL CARE, AND FULL POST NATAL CARE INCLUDING FAMILY PLANNING. APPROXIMATELY 400 OF THESE DELIVERIES OCCUR IN THE CENTER'S MATERNITY CENTER, WHICH HAD TO CLOSE FOR 6 WEEKS DURING THE SUMMER OF 1985 DUE TO THE LOSS OF MALPRACTICE/LIABILITY INSURANCE DESPITE THE FACT THAT THERE WERE NO CASES PENDING. DURING THAT PERIOD AT LEAST TWO INFANTS DEATHS COULD BE DIRECTLY AND CERTAINLY INDIRECTLY ATTRIBUTED TO THE CLOSURE AS INDIGENT WOMEN "FEARING" HOSPITAL COSTS AND DEPOSITS DELIVERED OR ATTEMPTED TO DELIVER WITH "PARTERAS".

SPECIFICALLY, ONE MOTHER REFUSED HOSPITALIZATION FOR CONTROL OF HER HIGH BLOOD PRESSURE AND DIABETES BECAUSE OF A FEAR OF

INCURRING A LARGE DEBT. SHE PRESENTED TO THE HOSPITAL ONLY AFTER SHE INDICATED TO A NURSE OVER THE PHONE THAT HER UNBORN CHILD HAD NOT MOVED IN OVER 12 HOURS. THE CHILD WAS STILLBORN. ANOTHER MOTHER CHOSE TO PRESENT TO A PARTERA RATHER THAN PAY A \$2,500.00 DEPOSIT AT THE HOSPITAL FOR IN-HOSPITAL PRE-NATAL MANAGEMENT, AND WENT ON TO DELIVER A 1½ POUND BABY. THE CHILD WAS TRANSFERRED VIA CAB IN A PLASTIC BAG TO THE EMERGENCY ROOM. THE CHILD DIED THREE DAYS LATER.

WITHIN THE HEALTH CARE INDUSTRY A MAJOR REORGANIZATION AND REDIRECTION IN HOSPITAL OWNERSHIP AND MANAGEMENT MAY RESULT IN THE CREATION OF MORE BARRIERS FOR INDIGENT PATIENTS REQUIRING HOSPITALIZATION. HOSPITALS AND THEIR ADMINISTRATION ARE TURNING TO THE CORPORATE MODEL WITH A RESULTANT INCREASE IN THE NUMBER AND PERCENTAGE OF FOR-PROFIT HOSPITALS. IN GENERAL, ACCORDING TO THE AMERICAN HOSPITAL ASSOCIATION IN THE NEXT FIVE YEARS THERE WILL BE FEWER AND LARGER HEALTH CARE CORPORATIONS. BY 1990 IT IS PROJECTED THAT ONLY 2000 CORPORATIONS WILL BE RESPONSIBLE FOR THE NATION'S HEALTH CARE, AS COMPARED TO THE 5000 IDENTIFIED IN 1980.¹¹ IN SOME AREAS OF THE COUNTRY, COMMUNITY AND OTHER NON-PROFIT HOSPITALS ARE BEING ABSORBED INTO THE "FOR-PROFIT" PATTERN, OR CLOSING THEIR DOORS DUE TO THE INCREASED PERCENTAGE OF NONREIMBURSED CARE THAT THEY ARE FORCED TO DELIVER.¹² HOSPITALS IN GENERAL ARE INDICATING THAT DUE TO SUCH REGULATIONS AS DRG'S, THEY ARE UNABLE TO "COST-SHIFT" THE BURDEN PLACED UPON THEM BY PROVIDING INDIGENT HEALTH CARE AND WILL NO LONGER BE ABLE TO PROVIDE AS MUCH "CHARITY CARE". THE EXPIRATION OR PAY-BACK OF MANY HILL-BURTON OBLIGATIONS HAS FURTHER DIMINISHED

THE NUMBER OF HOSPITALS WILLING TO PROVIDE INDIGENT CARE. UNLESS THESE TRENDS ARE REVERSED, AND THE DISEASE THE "FEAR FACTOR" ERADICATED, THE ULTIMATE COST IN LIVES AND MONEY WILL BE MUCH GREATER THAN THE PROJECTED SAVINGS BY HOSPITALS NOT WILLING TO CARE FOR THE INDIGENT, AS THE INDIGENT ARE FORCED TO WAIT UNTIL IT IS AN "EMERGENCY".

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Date: 2/10/85Mrs. Maria Etsa Penside # 19062-02has made the usual arrangements for her delivery at: Home
Barrow Air Medical Center 1134.00 per wk.
Willing to undergo Hospital X (which one) Birth Plan's onlyThis patient has made acceptable arrangements at this hospital Please see
for care at the time of her delivery.Patient's Signature
EOC 6-5-85For
Signature

Signature of representative of institution

NOTE: P.M. will not be available by the high-risk PL assigned
of Ironville Community Health Clinic until proof of
arrangements by the hospital where she wishes to deliver is
documented. Thank you.George J. Gibson, M.D.Anticipate C-Section Delivery.
Hospital exp. \$500.00
Clinic pay 700.00
\$2,800.00

Mini-

Can only pay \$250.00 - not enough!DATE: FEB. 21, 1985

11:20 A.M.

F/K - called Mrs. Penside's home, explaining above

P.S. DEL-EX

266
11

Date 11-20-65Mrs. Bea Pingo

has made financial arrangements for her delivery at

Dorchester Medical CenterValley Community Hospital ☒ (check one)This patient has made acceptable arrangements to be hospitalized
for care at the time of her delivery.Fin (Repeat) Check
ECC 4-20-65

Signature of Representative of Institution

NOTE: Patients may not be accepted at the high-risk or newborn
of Dorchester Community Health Clinic until proof of
acceptance by the hospital where she plans to deliver is
submitted. Thank you.

[Signature]
NIGHT ST. CLERK, JR.

Patient does not need required
deposit
Advice of 3500.00 deposit ^{11/20/65} ME

- had to be transferred to Dalton - and
it was not needed for one to two days
at Dalton patient contacted her other days
to go home & return in Jan. It was into
her sleep later. Husband lost job - now will
qualify for Medicaid - started very - also
I think from home.

The CHAIRMAN. Thank you very much.

Sara Rosenbaum, glad to have you here, and we look forward to your comments.

Ms. ROSENBAUM. Thank you, and thank you for inviting us to testify at this very important hearing this morning. Our written comments will be submitted for the record.

You have heard so many statistics that I am going to simply amplify a bit on what Dr. Smith said. I would like to underscore two points: one including the magnitude of the problem, and the second being what ought to be done about it.

First, I want to underscore and expand upon what Dr. Smith is describing in Brownsville. We have been working with the Brownsville clinic now for several years. In the interim, the kinds of problems that are occurring in Brownsville are beginning to show up in other parts of the country, parts of the country where we like to think that there is some basic health safety net in place that would prevent the occurrence of situations like David's.

The growing number of children without health insurance and the growing number of women of child-bearing age without health insurance means that today between 55 and 60 percent of the 35 million uninsured Americans are women of child-bearing age and children. And, therefore, pediatric and obstetrical health issues jump to the fore when one knows the problem of medical indigency in America.

This summer, CDF conducted a nationwide study of the availability of residual public health services for uninsured women and children. We looked specifically at maternity care and primary pediatric services that is, those services provided by health departments that are not classified under states' so-called Crippled Children's Programs, which are programs for children suffering from certain handicapping conditions.

Our findings were extremely grim. First, we found that there were four states in the country that offer absolutely no publicly subsidized outpatient maternity care. A poor pregnant woman living in one of the four states has nowhere to turn.

However, only 13 states offer subsidized outpatient prenatal care programs on a state-wide basis. Only one of those 13 states, Massachusetts, was sufficiently funding its program to meet all of the state's need as a defined need. But even that state did not define need to include all uninsured women. So we have no doubt that there are women even in Massachusetts who are in need but are not being reached by the Healthy Start Program.

Probably the most sobering part of the survey is that only 23 states provided any assistance with inpatient maternity care for uninsured women. This is a very serious shortcoming, since 28 states also reported that hospitals were dumping pregnant women in either the early or late stages of labor.

The CHAIRMAN. What happens in those other places? Twenty-three states are providing that. What is happening in those other places?

Ms. ROSENBAUM. Things are occurring: The first, as David is describing, is many out-of-hospital births. Out-of-hospital births are a big problem in southern Texas. We have known that for a long time. In Oregon the state has also noticed a sizable increase in out-

of-hospital births among women who simply report that they do not have a way to pay for the deliveries. The second response to the problem is that women are showing up at hospitals in labor, and it is because they delay until they are in active labor hoping to be admitted. One hospital dumping finding in our survey is thus of great importance because of its magnitude. Of the 28 state health agencies reported patient dumping pregnant women in labor, 15 indicated that hospitals were turning away women in active labor as opposed to just the early stages of labor.

Our findings were done right before the effective date the new law, the anti-dumping in whose enactment Senator Kennedy played such an instrumental role. However, David Smith's cases and others in which we are now currently involved occurred about two or three months ago. So, in fact, hospitals are continuing to turn away women in active labor.

In addition to patient dumping, 23 states reported that hospitals were using pre-admission deposits. Pre-admission deposits are a very lethal, very effective, tool for keeping patients out. Sometimes they are as shockingly high as the \$3,500 deposits David described. But if you recall some of the testimony from the first panel this morning, a hospital can demand a deposit of \$200 and effectively steer away virtually the entire low income, uninsured population residing in its service area.

Most interestingly, virtually every state with an uncompensated care hospital financing system, including either rate setting or pooled systems for paying for uncompensated care, reported problems with the use of pre-admission deposits. Why, one wonders, does this occur, since hospitals in these states theoretically are paid for serving uninsured patients.

Yet there are several reasons why even hospitals in uncompensated care states do not want to admit these women. In some cases, it is because their rates will go up as they take more uninsured patients. That is true in a state like Maryland. In a state with a pooling system, there is reportedly fear about exhausting the amount of pooled funding. South Carolina is a good example of a state in which the pooling ran out midway through the year. Hospitals obviously did not want to provide the care only to discover that the pool of money had been exhausted.

Finally, the medical staff of many hospitals simply do not want the kinds of patients who are showing up in early or active labor, have probably had little or no prenatal care, and may be more complex patients to handle.

Turning to pediatric care, only 13 states offered any primary pediatric service systems on a state-wide basis for uninsured children. Of these none had a state-wide system that included treatment. The only services available state-wide were check-up and immunization programs. For example, if a child was screened and found to have strabismus an eminently treatable condition, no state had statewide ophthalmology program to which children could be uniformly referred.

The level of state-wide primary source programs is compounded by the fact that twenty states still fail to extend Medicaid coverage to all children between the ages of 5 and 18 living below state poverty levels.

Finally, in only two states was hospital assistance available for sick children who do not meet the definition of crippled children. Yet many state crippled children's programs exclude such killers as cancer, diabetes, sickle cell anemia and asthma from coverage.

The cost of the kinds of policies that we are pursuing, particularly our maternity and infant care policies, or lack thereof, is enormous in both human and financial terms. CDF is currently completing work on a major study which we will make available to the Committee in about two weeks. Among other issues, the study examines the number of excess low birth weight births that the nation will experience this decade because it has failed to meet the Surgeon General's 1990 low birth weight goals.

Our preliminary conclusion is that the number of the excess low birthweight births are in the hundreds of thousands. That is, several hundred a thousand of excess low birth will occur in the United States during this decade because we have not reduced low birthweight.

Moreover, our study includes a calculation of the cost to the nation of these excess low birthweight births. We examined only the first year costs of caring for these infants, because it becomes much too difficult to calculate outyear costs. Fortunately, or unfortunately, however, there are very identifiable costs for the first year of caring for low birthweight infants. Just the first year costs of furnishing hospital and medical care for these infants is in excess of two billion dollars. And if we could carry these cost calculations number out over the lifetime of these infants and factor in special medical, social and educational costs, as well as lost productivity, we think that the number is probably in the tens of billions.

For the same money, we obviously could have provided comprehensive maternity and pediatric care to almost any woman or child in the country who did not have adequate resources. And we would have also provided the kind of services that tend to bring down low birth weight rates and this could have saved money.

Turning to remedial issues, what has struck me most about this morning is that this Committee really needs to come to grips with what we mean by insurance. We think of insurance and we all talk about insurance as a high risk catastrophic subsidy. Actually, in the United States insurance is very different from that. Insurance represents a vital subsidy for a lot of routine health benefits. Those of us who are fortunate enough to have good-paying jobs and comprehensive insurance plans have this subsidy. And a lot of us, even those of us who are middle class would find it very difficult to get along without this governs subsidy.

Thus, when you think about remedies in fashioning insurance relief for families under age 65, you need to think about the nature of those families and their needs. Many are working, but the problem with, an employer-based insurance remedy is that many of the people who are working are employed at jobs where turnover—to give you an example given to us by the Pillsbury Company—is 250 percent a year at its Burger King subsidiary. An employer-based remedy may not be appropriate in that kind of setting and it certainly does not reach unemployed uninsured families.

Employer-based coverage the poor does not provide the right benefit package, particularly for children, and particularly where maternity and pediatric care is concerned.

We strongly recommend that the Committee look at changes in programs such as Medicaid which would permit the working poor to buy medicaid coverage on a subsidized basis, similar to the tax subsidy that we all receive under our employer-based plans, and which is the second largest health program we run in this country. We also need a series of supplements to programs such as the Community Health Centers Program, the Title V Maternal and Child Health Program and WIC, so that at the minimum there, no woman or child goes without primary services because of lack of health insurance.

Finally, we would ask that the anti-dumping provisions enacted by Congress last year be expanded to prohibit the use of pre-admission deposits in the case of maternity delivery services at a minimum.

Thank you.

[The prepared statement of Ms. Rosenbaum, with an attachment, follows:]

Testimony by The Children's
Defense Fund
Before the Senate Labor & Human
Resources Committee Regarding
Access to Health Care

Presented by
Sara Rosenbaum
Director, Health Division

January 12, 1987

Mr. Chairman and members of the Committee;

Thank you for inviting the Children's Defense Fund to testify at this important hearing. For 25 years the Children's Defense Fund, a national public charity, has conducted extensive research into low income children's health status and access to health care. We have also advocated for fundamental improvements in the scope and structure of major federal, state & local health programs and policies. We congratulate this Committee for so promptly turning its attention to one of the nation's most pressing public policy issues: inadequate access to health care for so many Americans.

We are here today to report that low income children face a growing crisis in gaining access to health care. This crisis has struck at a time when poverty and health indicators demonstrate the need for generous health interventions, and the cost of permitting the disinsurance of poor children to continue unchecked is extraordinary in both human and financial terms.

Growing Childhood Poverty

Between 1979 and 1982, the number of American children living in poverty grew by over one-third.¹ Poverty rates have abated only very slightly since then; for hispanic children, they have continued to grow.² The causes of widespread childhood poverty are deep and will not abate soon. They include: the growing number of female-headed households; persistently high unemployment; and the decline in real income that has resulted from the disproportionate growth of low paying jobs and the failure to raise the minimum wage since President Reagan assumed office.

It is also clear that the chief culprits underlying childhood poverty are economic, rather than family composition, factors. Even had family composition retained its 1970s configuration, childhood poverty nonetheless would have increased dramatically in the 1980s. Table I.

The Loss of Health Insurance

America relies primarily on out-of-pocket payments and employer-provided private health insurance to finance health care for families with children.³ When widespread poverty strikes, it takes a tremendous toll on families' access to health care in two ways. First, growing impoverishment means the loss of disposable income for meeting out-of-pocket health care costs. A person who is the head of a head of a four-person family and earns \$5.00 per hour is supporting his or her family on \$800 per month -- less than 80 percent of the federal poverty level for a family of that size. Under these circumstances the family is without the disposable income needed to purchase even basic services.

Second, the same employment patterns that are causing impoverishment, particularly the gradual replacement of higher paying jobs with lower paying jobs, are also contributing to the disinsurance of children. More Americans are now working for employers who offer no insurance. Moreover, many employers are reducing their contribution to their employees' health plans, particularly in the case of dependent coverage, thereby leading to the disinsurance of families that cannot afford to meet these increased costs. Furthermore, employers are taking other steps that effectively disinsure their workers such as imposing larger deductibles and lengthier "lag time" requirements on new workers. Finally, employers are making greater use of part-time employees, who frequently do not qualify for fringe benefits.

These employer-provided insurance trends have occurred simultaneously with a substantial erosion in Medicaid eligibility, including the failure to increase financial eligibility levels, as well as the virtual elimination of working poor families from the program by the 1981 budget cuts.⁴ As a result of these two simultaneous trends, by 1984 nearly 12 million children under age 18, and over 9 million women of childbearing age, were uninsured.⁵ Three quarters of all uninsured children, and two-thirds of uninsured women had family incomes below 200% of the federal poverty level,⁶ and the great majority lived in working families.⁷ The more than 20 million uninsured children and women of childbearing age constituted between 55% and 60% of America's 35 million uninsured that year.

Child Health Indicators

Virtually simultaneously with the growth in poverty and loss of health insurance coverage there have occurred a series of troubling maternal and child health trends. These include:

- o A virtual stagnation in the rate of decline in infant mortality; 8
- o A black/white infant mortality "gap" in 1983 of 1.98 -- the highest in over 40 years. 9
- o A nationwide increase in postneonatal mortality in 1983; 10
- o Failure to improve the percentage of women receiving early prenatal care. 11 During the 1979-1984 period, when poverty and disinsurance increased, the percentage of pregnant women beginning prenatal care early in pregnancy completely failed to improve. In 1984, one in every 5 white infants, and 2 in every 5 black infants, was born to a woman who had failed to receive prenatal care early in pregnancy. During the 15 years preceeding the 1979-84 period, when public health funding was increasing, the number of women receiving care early in pregnancy grew by over 20%.

- o Persistently high low birthweight rates. America's low birthweight rates -- the leading killer of infants, and a leadingcrippler as well, remains one of the highest among industrialized countries.

Failure of Residual Public Health Programs

Persons without health insurance -- public or private -- receive 55% less physician services and 90% less hospital care.¹³ Uninsured low income persons are wholly dependent on residual public health programs for the care they receive. Yet a nationwide study of residual public health maternity and pediatric health services (other than crippled children's services) provided by state health agencies which was conducted by CDF in 1986 (and which is included with this testimony), revealed the following:

- o Four of 51 jurisdictions have no public prenatal programs. Among the remaining 47, only 39 make their programs available to all pregnant women, as opposed to only certain classes of poor pregnant women, such as "high risk" or single women.
- o Only 13 of the 47 states with public prenatal care offer statewide public programs, and only one -- Massachusetts -- reports funding levels sufficient to meet its own defined levels of need (which do not include all uninsured women).
- o Only 23 states were able to provide any uninsured women any inpatient delivery assistance. Twenty-eight states reported that hospitals were dumping pregnant women in either early or active labor. Twenty-three states reported that hospitals were demanding preadmission deposits. Only 4 could state categorically that preadmission deposits were not a problem.
- o In only 13 jurisdictions was any level of primary pediatric care available statewide, and statewide services were limited to immunizations and preventive exams.

- o Only two states covered inpatient hospital care for children not categorized as "crippled." Common diagnoses excluded from state Crippled Children Services programs include sickle cell anemia, diabetes asthma and cancer. All of these diseases are killers and cripplers.

The Cost of Inadequate Care

A lack of adequate health care is taking an immense human and financial toll on both children and the nation. CDF is currently completing work on a major study which examines, among other things, the number of excess low birthweight births that will occur between 1978 and 1990 because of our failure to meet the Surgeon General's 1990 low birthweight goal. Preliminary results indicate that this number will be in the hundreds of thousands. Moreover, our preliminary estimates also indicate that the excess first year costs alone of caring for all of these low birthweight births that should not have occurred will be in the billions of dollars. The longterm costs of caring for these infants may climb into the tens of billions of dollars. For this money we could have paid for health and nutritional services for virtually all of the women and children who needed them.

RECOMMENDATIONS

It is essential that steps be taken immediately to expand and improve a variety public health programs in order to provide assistance to persons without health insurance. We recommend modification of Medicaid to permit families to buy coverage on

the basis of an income-adjusted premium. We also recommend supplementation of the Title V Block grant and the Community and Migrant Health Centers program in order to permit development of providers in all medically underserved areas of the country.

In addition, we recommend that this Committee amend federal law to establish minimum content and costsharing requirements for all employer furnished health insurance plans and to require all employers to either furnish affordable family health insurance coverage.

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Table 1
 Poverty Rates among Children
 Related children living in families
 in 1979 and 1983, by Race and Hispanic Ethnicity
 with 1983 Poverty Rates Adjusted to 1979 Family Structure

	Total	White	Black	Hispanic
1979 Actual Poverty Rates:				
Total, all children	16.6	11.6	48.6	27.7
Female-headed families	48.6	18.6	63.1	48.2
Other family structures	6.5	7.2	18.7	16.2
1979, percent of all children in female-headed families	18.78	13.18	63.77	16.77
1983 Actual Poverty Rates:				
Total, all children	28.1	15.8	60.1	28.6
Female-headed families	53.6	45.2	62.0	72.0
Other family structures	11.7	18.6	18.6	27.6
1983, percent of all children in female-headed families	58.92	18.88	58.55	27.11
1983, poverty rates adjusted to 1979 family structure:				
Total, adjusted	19.3	14.8	45.7	28.2

Adjusted rates are computed by using actual 1983 poverty rates for female-headed and other families, but assuming the percentages of children living in female-headed families from 1979.

RESULTS OF A 1986 NATIONWIDE SURVEY OF STATE TITLE V
MATERNAL AND CHILD HEALTH AGENCIES'
PROGRAMS FOR MEDICALLY INDIGENT PREGNANT
WOMEN AND CHILDREN

Presented at the Annual Meeting of the
American Public Health Association,
Las Vegas, Nevada
September 30, 1986

Sara Rosenbaum

Dana Hughes

Kay Johnson*

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- *. The authors are deeply indebted to Michael Pignone and Tamara Lewis who, while interns in the CDF health division during the summer of 1986, administered the survey contained in this paper.

INTRODUCTION

"The regionalized perinatal health system is designed for women and children with private health insurance."

"[Uninsured] pregnant women sit on the steps of the hospital when they go into labor."

-- Statements by maternal and child health
agency officials interviewed in two states

Millions of low-income children and women of childbearing age are completely uninsured. The Alan Guttmacher Institute has estimated that in 1984, 36% of America's 9.5 million poor women, and 30% of America's 5.1 million near-poor women of childbearing age were completely uninsured.¹ The Urban Institute reports that one-third of all poor children, and 29% of all near-poor children under age 18 were also uninsured that year.²

This epidemic lack of health insurance among low-income women and children most certainly has not abated over the past two years. Several causes probably account for the phenomenon, including the following: the increased prevalence of low paying jobs that provide poor wages and no fringe benefits such as health insurance;³ unemployment;⁴ the growth of single-parent headed families, resulting from increased divorce and out-of-wedlock childbearing rates,⁵ that are significantly more likely to be completely uninsured;⁶ declining employer support for employees' job-related health insurance costs;⁷ welfare stagnation since the early 1970s that resulted in depressed Medicaid eligibility levels;^{7a} and cutbacks in public health programs since 1981.⁸

Medicaid, the nation's largest public health financing program for the poor, is an inadequate resource for uninsured families with children. By 1984, the program served only 46% of the poor and near-poor, down from 65% in 1976.⁹ Moreover, only about half of all poor and near-poor child Medicaid enrollees have coverage on a full-year basis.¹⁰

Medicaid's inadequacies stem from several factors. First, financial eligibility standards are extremely low. Appendix A sets forth states' 1985 AFDC and Medicaid eligibility standards for families with no other income. The average state income eligibility standard in 1986 was roughly 47% of the federal poverty level.

Second, severe categorical restrictions against coverage of children still persist. As of 1986, approximately 19 states¹¹ still failed to extend Medicaid to all poor children over age 5 (including those living in two-parent families), regardless of how poor they were. Finally, Medicaid eligibility criteria for families with children incorporate the financial eligibility standards and budgeting methodologies utilized to determine eligibility for AFDC benefits and thus, inherently discriminate against the working poor,¹² who represent the very poor persons most likely to be completely uninsured¹³

Some relief against Medicaid's inadequacies might be found in state-financed programs for the medically indigent. In 1985, thirty-three states and the District of Columbia maintained statewide general medical assistance (GA/MA) programs for individuals and families who were medically indigent and otherwise ineligible for Medicaid.¹⁴ Additionally, seven states

currently maintain a statewide system for financing uncompensated hospital care.^{14a} However, state GA/MA programs frequently utilize extremely restrictive eligibility criteria. Indeed, it is not uncommon for GA/MA eligibility and coverage standards to be even more restrictive than those used under Medicaid.^{14b} Furthermore, four of the thirty-four GA/MA programs were not operational in 1985.^{14c}

Given the obvious inadequacy of both Medicaid and GA/MA programs in meeting the health needs of medically indigent pregnant women and children, the Children's Defense Fund undertook a survey of Title V Maternal and Child Health agencies in all 50 states and the District of Columbia during the summer of 1986 in order to determine the range of services that these agencies provide in addition to Medicaid, GA/MA, and states' uncompensated hospital care programs. The purpose of this paper is to present the results of our survey.

METHODOLOGY AND LIMITATIONS OF THE SURVEY

In order to conduct this survey, CDF prepared a thirteen-page written survey instrument. The instrument contained questions about four distinct types of maternal and child health services. It also sought to elicit information about the impact of the Balanced Budget Act of 1985 (popularly known as the Gramm/Rudman/Hollings Act) on the activities of Title V maternal and child health programs. Finally, the survey sought to measure the prevalence within each state of hospital-based barriers to admission of low income, uninsured patients. The two most prevalent types of barriers which we were most interested in

assessing included the overt practice of turning persons away (known as "dumping") and the more subtle but equally normal practice of imposing inaffordable preadmission deposits as a condition to the rendering of care.

CDF was particularly interested in learning more about hospitals' use of preadmission deposit requirements. Unlike may hospital emergencies which cannot be anticipated, labor and delivery is an event which can (and should) be planned for, so that a woman can deliver her infant in the most risk-appropriate setting. Medical experts have consistently pointed to risk-appropriate deliveries as one of the most fundamental elements of quality maternity care program. But, preadmission deposits effectively prevent indigent pregnant women from registering in advance for delivery, thereby forcing them to arrive in emergency labor at a hospital's emergency room. This situation can obviously place both the mother and her infant at danger, as well as denying her the possibility of a planned delivery at a risk-appropriate facility.

CDF hypothesized that, given the modest nature of federal and state funding for Title V Maternal and Child Health programs and activities (\$478 million total federal funding in Fiscal 1986, prior to the Gramm/Rudman 4.3% sequestration order), as well as the major strains imposed on the public health system by the widespread lack of health insurance among poor women and children, Title V programs would be seriously inadequate to meet widespread need. We also hypothesized that the Balanced Budget Act would already have had some measureable effect on the

planning and service delivery activities of state agencies, since the Act did not shield Title V against the 4.3% sequestration order that took effect in March 1986.¹⁵

The survey instrument was administered by telephone to all 51 Title V agencies during July, 1986. In some states, agency directors responded themselves. In others, directors referred us to staff who would be able to provide us with the information we sought. We were able to complete the survey for all 51 agencies. A number of agencies provided us with additional written information on program expenditures and activities.

Because the scope of Title V activities are so broad, we limited the pediatric portion of our survey to investigation of services other than Crippled Children's services. State Crippled Children's programs are quite specialized, often dealing with only a small range of the illnesses and conditions that affect children. Moreover, in 1983, they served only 650,000 children, many of whom may not have been technically "low-income."¹⁶

In many states, crippled children's eligibility criteria are so restrictive that even such conditions as cancer, sickle cell anemia, diabetes, traumas, accidents, and other relatively common serious child health problems are not covered by the program.^{16a} Thus, the availability of non-CCS outpatient and inpatient diagnostic and treatment services is a matter of concern, not only to the millions of uninsured poor and near-poor children needing routine pediatric care, but to thousands of seriously ill children, as well. It was thus our desire to measure the availability of services for low-income women and for children falling outside a state's crippled children's network.

CDF's survey questions dealt with eligibility, financing, and scope of care for four major groups of MCH services. These include: outpatient maternity care; inpatient maternity care; outpatient pediatric care, including well-child and acute care services for common childhood ailments and conditions; and inpatient pediatric services (excluding services for routine hospital newborn care) for children not suffering from an illness or condition designated as "crippling" by the state's Crippled Children's agency.

This survey contains a number of limitations that should be noted. First, we confined our survey to state administered maternity and pediatric programs. Thus, we might have overlooked independent local programs. For example, a county or city might offer a comprehensive maternity or pediatric health program that is wholly independent of state funding or oversight. Similarly, there might be several wholly-federally funded Community or Migrant Health Centers operating within a state, that are capable of furnishing care to all medically indigent women and children residing in their catchment areas. However, we believe that completely independent, comprehensive local public health programs are not common. Moreover, health centers now serve only 5 of America's 25 million underserved persons.¹⁷

Second, we attempted to screen out those programs that Title V officials had no jurisdiction over, such as GA/MA programs or uncompensated hospital care programs administered by other agencies. The purpose of this survey was to identify MCH-specific programs that supplement general state programs for the

medically indigent.

Third, the responses here are those given by maternal and child health agency officials themselves and thus, the data are self-reported. If anything, this survey appears to underestimate the scope and depth of poor access to care. For example, the responses given by the California agency vary with analyses done by outside organizations. In Minnesota's and Rhode Island's cases, the responses given describe less serious problems than those presented in analyses done by the agency heads for their state legislatures.

Fourth, this survey did not measure either the quality or depth of services. A state official might report the existence of "well child" or "prenatal" clinics in every county. We did not attempt to measure, however, whether services were of uniform scope, depth and quality throughout the state or whether long waiting periods for appointments existed. Frequently state officials simply did not have this information. The unmet need estimates presented in Appendix C shed some light on the shortcomings of even statewide service systems.

OVERALL CONCLUSIONS

This survey yielded three major overall findings. First, in many states there exists a profound shortage of comprehensive, affordable maternity and pediatric services for low-income, uninsured women and children. Second, state maternal and child health agency directors are struggling with the impossible task of having to make what is essentially a modest categorical program that may be adequate to underwrite planning, development,

standardsetting, evaluation and demonstration activities, into a cure-all for the massive shortcomings of the nation's public and private health insurance systems. Third, given the severe shortages that already exist, the first wave of Gramm/Rudman cutbacks were unconscionable. Another round would be simply unthinkable.

These overall conclusions are based on a series of responses provided by state officials to the questions we posed regarding the four target groups of maternal and child health activities.

MATERNITY CARE

1. Outpatient Care

a. Existence of programs

As Appendices B and C indicate, 48 out of 51 agencies reported that they offer at least some prenatal care. Thirteen respondents reported that prenatal care services were available on a statewide basis, while 10 agencies reported that their programs targeted one or more areas demonstrating high need.

Appendix B indicates that even statewide and/or targeted programs fail to assure that all needs are met, however. Only one state, Massachusetts, reported maternity program funding levels that were adequate to meet the needs of the entire target population. A second state, Michigan, is in the process of increasing funding levels for its statewide maternity program to ensure that the needs of the target population are met.

It should be pointed out that the definition of "unmet need" varies significantly from state to state. While six states report that they target virtually any woman without adequate health insurance, only one of these states, Rhode Island, indicated that it targets all uninsured women who need were assistance. Most states impose income eligibility requirements under their programs, and others impose additional requirements such as single status or high risk. Obviously the definition of "unmet need" plays a crucial role in measuring how adequately a state's program responds to that need.

b. Eligibility criteria

- 1) Categorical eligibility standards:
among the 47 agencies reporting one or more prenatal programs, 39 extend the programs to women on the basis of pregnancy alone. Eight states report that all or some of their programs are limited to "high risk" women. One state requires that women be single. One state requires that the woman be a member of an unemployed family.
- 2) Financial eligibility standards: thirty-six states report using uniform financial eligibility criteria in determining eligibility for services. Another twelve states reported either that income eligibility varies by locality or that there exist no eligibility requirements.

Most states with established income eligibility criteria report that services are furnished free of charge to certain classes of women (e.g., those with family incomes below 100%, 150% or 185% of the federal poverty level). However, anecdotal evidence suggests that many clinics now routinely bill all maternity patients for care and only later forgive bills incurred by women falling into a "free care" category.¹⁷ Most agencies with uniform financial eligibility criteria also report making services available in accordance with a sliding fee scale to women with family incomes over the "free care" level.

c. State contributions to prenatal care programs

The Title V Block Grant Act requires that states provide matching funds for the federal financial assistance they receive.¹⁸ These state matching funds may be spread among all Title V services or concentrated within certain service categories, so long as they are legally sufficient. Our survey revealed that forty states have currently appropriated state funds for prenatal care services. (Appendix E) This funding may reflect both the state's mandated matching obligation under Title V, as well as additional appropriations beyond those required by law. Washington State officials reported that funds from the state's home heating program are used to furnish

prenatal services. North Dakota officials reported that they use funds from the state's alcoholism program for prenatal care. Eight states were able to identify other funding sources, including local funds, that support prenatal programs.

2. Inpatient Services (Appendices D & E)

While the overwhelming majority of state agencies now fund prenatal care in at least some areas, the picture is far different with respect to inpatient care. This is particularly disturbing. While high quality, early, and continuous prenatal care is essential to a healthy birth outcome, equally essential is a planned delivery at a risk-appropriate facility. Indeed, some of the greatest strides in infant mortality reduction over the past twenty years have resulted from the development of specialized inpatient maternity and newborn care.¹⁹ CDF's survey revealed however, that planned, risk-appropriate inpatient delivery services may be unavailable to the women who need them most.

As Appendix H indicates, 15 state agencies reported that hospitals were denying admission to women about to deliver. Another 13 reported that hospitals were denying admission to women not yet in "active" labor.* Six additional states were

* The office for Civil Rights of the Department of Health and Human Services classifies "active labor" as labor in which the pregnant woman's cervix is more than 5 centimeters dilated. The Medicare protections against patient dumping that were recently enacted by Congress classify "active labor" as labor in which delivery is "imminent." Thus, many women who are not yet in "active labor" (such as a pregnant woman in the early stages of labor with a known breech presentation) may still pose clear emergency care needs.

aware of hospital "patient dumping" but didn't identify the specific populations that were affected. Only 14 agencies reported that patient dumping was not a problem. Four agencies did not know whether or not "dumping" was a problem.

Additionally, 23 agencies reported that one or more hospitals in the state imposed preadmission cash deposit requirements on pregnant women. Only four agencies were able to report that deposits were not a problem. The remaining 24 did not know whether or not deposits were a problem.

Preadmission deposits effectively prevent uninsured, indigent pregnant women from registering early, and in advance, for delivery services. As a result, high quality delivery services may be unavailable until a pregnant woman is in advanced labor and therefore an emergency case.

We thought it particularly noteworthy that officials in nearly all of the states with uncompensated hospital care programs either reported the existence of one or more types of hospital admission barriers in the case of maternity patients. Some of this may result from the imperfect nature of these programs. For example, in a rate-setting state such as Maryland, hospitals may not want non-paying patients, because their rates are driven up. In states such as New Jersey and New York, hospitals may deny admission, because uncompensated care funds are finite in amount and thus run out. In other states, staff physicians may desire to avoid certain women as patients, and a hospital may tacitly respond by erecting financial barriers. As a result, medically indigent pregnant women may not be protected

even in these states.

Despite the acute problems posed by budgeting and professional depletion, few state agencies report having any important funding resources. Only 22 states reported the existence of important funds, and 16 of these reported funds either to assist the participation in various designated emergency care programs or to meet the acute identified as high need groups in the labor and delivery period. This latter situation is problematic, since approximately 20% of the states that emerge during the perinatal period do not establish themselves until the labor and delivery phase of pregnancy.²²

No state has a program that provides adverse assistance to all interested women who do not have the resources to pay for expensive hospital care and therefore cannot register for delivery services. Emergency assistance to pay all services are to be reduced.

Factors in the 7 unrepresented care states may also signal the general unwillingness of hospitals and physicians to furnish care to certain women. State officials in Michigan reported, for example, that obstetricians in Kalamazoo and surrounding counties providing obstetrical services to patients involved in structured programs across the state of legal liability toward women with whom they have had no previous relationship. Similar problems have arisen in Massachusetts, Virginia, Florida, New York and California.

PEDIATRIC CARE

1. Outpatient Servicesa. Existence of program

Forty-six states reported the existence of pediatric outpatient programs. In 13 states, some level of services was reportedly available on a statewide basis.

b. Eligibility1) Categorical eligibility:

Seven states maintained pediatric programs limited to only certain ages of children. Three of these states imposed an age requirement as low as two years or younger. One state confined its program to high-risk children.

2) Financial eligibility:

Reflecting the far greater level of discretion accorded localities in providing pediatric services, only 23 states reported using uniform income eligibility standards at all service sites. Of these, at least one agency indicated that the actual standards used from site to site would vary. Those agencies that had not established uniform criteria or that expressly permitted localities to set standards, did not know what standards were in effect.

The lack of uniform income eligibility levels for pediatric care underscores the fact that, as many states indicated to us, pediatric services are often viewed as an elective service within a county health department and therefore out of the purview of the

state Title V agency. This lack of state-level involvement is also reflected in Appendix B, which reveals that while unmet needs assessments are frequent in the case of maternity care, they are virtually absent in the case of pediatric services.

3) State contributions

Only 23 agencies reported the existence of state appropriations for the provision of outpatient pediatric services. (Appendix G)

4) Services

All agencies reporting the existence of outpatient programs offered "well child" care. In the great majority of states offering "well child" services, care is available on a statewide basis. However, no agency provided either comprehensive services or services for acute care needs on a statewide basis. Indeed, only 11 states reported furnishing any acute care services at all, and officials in many instances indicated that the only remaining acute service programs were remaining Children and Youth Project sites.²¹

5) Participating providers

Nineteen agencies reported that outpatient pediatric care was furnished exclusively by local health departments. Since local health department staff frequently engage in a more limited scope of practice than either private physicians or community health centers, this means that health staff would be unable to provide any treatment for a child presenting

with an illness or condition. Thirty-two states made use of private providers, community health centers, hospitals, and other clinics, all of whom could provide comprehensive, or at least acute, care.

2. Inpatient Services

Only two states reported the availability of any Title V financed or administered pediatric inpatient programs for children other than crippled children. Kentucky maintains a limited inpatient program for poor children under age 12 who are ineligible for the Crippled Children's Program and Louisiana operates a statewide program financed with state funds. South Carolina reported the existence of some locally funded children's hospitalization programs for poor, non-CCS children, but the state appears to play little or no role in administering the program.

Given the highly restrictive nature of many CCS programs and the fact that about 20 states do not furnish Medicaid to children over age five living in poor two-parent families, this leaves low-income children needing acute outpatient or inpatient hospital care with virtually no recourse, unless the state happens to be one of the seven with an uncompensated hospital care program. Three states were specifically aware of patient "dumping" practices involving children. Officials in Louisiana told CDF that uninsured women and children simply would not use institutions other than the charity hospital system.

THE EFFECTS OF GRAMM/RUDMAN

Against this grim backdrop, the notion of service reductions is simply untenable. Yet Appendix G indicates that 15 states reported that the 4.3% reduction in Title V funding arising from the March, 1986, sequestration order had already led to the reduction of services. The following specific reductions were reported:

- o cuts in pediatric inpatient hospitalization for crippled children from 10 days per year (which already represented a reduction due to previous cutbacks) to \$10,000 per case (ID);
- o reductions in family planning services (MI);
- o outreach and home visiting services (MS); and
- o prenatal and "well child" care (NM).

The remainder cited general, across-the-board reductions in all activities.

Every state reported that further sequestration would make actual service cuts unavoidable. Many had avoided service cutbacks this year by using carryover funds. By the end of Fiscal 1986, however, all carryover monies will be gone. Thirty-two agencies reported that their state had already established a policy of refusing to replace any sequestered funds.

Thirteen states reported that future reductions resulting from sequestration would be absorbed across-the-board. Thirty-one states indicated that cutbacks would be targeted to specific programs and activities. Examples of targeted cutbacks, described in Appendix H, include the following:

/

- o Cessation of the SSI Disabled Children's Program (AZ);
- o Reductions in funding for C&Y and MIC projects for high-risk mothers (HA) (ID);
- o Elimination of services for older children (LA);
- o 6122 fewer maternity patients, 10,000 fewer family planning patients and cessation of the Medicaid outreach and enrollment program, even though Medicaid is not affected by Gramm/Rudman (MI);
- o Reduction of CCS services (MT, NV);
- o Prenatal, maternity inpatient, "well child" care (NM);
- o Prenatal, family planning, pediatrics (ND);
- o "Well child" care (OR);
- o Maternity hospitalization (VA);
- o CCS reductions (WV).

CONCLUSION

Between 1978 and 1984, the number of uninsured Americans grew from 28 million to over 35 million.²² One-third of the uninsured -- the largest single group of uncovered Americans -- are children.²³ Another nearly one-quarter are young adults between the ages of 18 and 24,²⁴ including millions of young women in their prime childbearing years. Two-thirds of the uninsured in 1984 had family incomes of 200% of the federal poverty level or less.²⁵ Three-quarters were workers and their dependents.²⁶

Medicaid, with its restrictive categorical and financial eligibility standards, is clearly inadequate to fill the gaps in the private system, as are states' general medical assistance

programs and uncompensated hospital care programs. This survey underscores that Title V agencies, with their modest resources and, frequently, limited authority over state public health activities, cannot even begin to meet the void, particularly where acute pediatric outpatient services and inpatient maternity and pediatric care are concerned.

Particularly disturbing may be the pediatrics picture. In recent years, as the decline in infant mortality rates has slowed, public emphasis has been placed on prenatal care as key to the reduction of infant mortality, which it most certainly is. However, close examination of infant mortality patterns reveals that great problems are occurring in the postneonatal period as well, when access to comprehensive pediatric health care is vital. Literally no state makes such care available to all poor infants in need. Moreover, postneonatal mortality, with its sensitivity to environmental factors, may be an indicator of the generally poor health status of lower-income children. Put another way, babies may be succumbing to deprivations that older children are sturdy enough to survive, but at great cost. Thus, postneonatal mortality may well be an indicator of health problems among all ages of children and thus raises major concerns about the absence of comprehensive child health programs.

In recent years, Congress and the states have paid greater attention to unmet maternity needs, and notable progress has been made. That progress must be expanded and deepened, particularly with respect to inpatient services. We must also, however, place equal emphasis on improving access to pediatric services.

The question of how further funding if any, should be invested is extremely important. Studies have cited the disparity in health care utilization between insured and uninsured low-income children reliant exclusively on public health services.²⁷ Even a significant Title V expansion would not constitute health insurance. We believe that the Title V program should not play the role of a medical financier, since a categorical grant financing approach simply does not provide the same degree of access to a comprehensive range of inpatient and outpatient care as that afforded by public and private insurance.²⁷ Title V is an essential planning, delivery and management device, but meeting the access gaps described in this paper will require a substantial public and private insurance expansion.

Footnotes

1. Gold, Rachel and Kenny, Asta, "Paying for Maternity Care" 17 Family Planning Perspectives 105 (May/June, 1985). The term "poor" is defined as family income below 100% of the federal poverty level, and "near-poor", as family income between 100 and 150% of the federal poverty level. In 1984 the federal poverty level was \$10,200 for a family of four.
2. Sulvetta, Margaret and Swartz, Katherine, The Uninsured and Uncompensated Care (prepared by the Urban Institute for the National Health Policy Forum, Washington, D.C.) June, 1986.
3. Swartz, Katherine, "Who Is Uninsured and What Can Be Done?" (Urban Institute, 1984).
4. Children's Defense Fund, A Children's Defense Budget, Washington, D.C., 1986.
5. Congressional Research Service, Children in Poverty (Washington, D.C., 1985).
6. Sulvetta, op. cit.
7. Rosenbaum, Sara, "Children and Private Health Insurance," [forthcoming in] Recent Developments in the Financing and Organization of Health Care: Implications For Children.
8. See, e.g., General Accounting Office, An Evaluation of the 1981 AFDC Changes: Final Report (Wash., D.C., 1985).
9. Robert Wood Johnson Foundation, 1985.
10. Wilensky, Gail and Berk, Mark, "Health Care, the Poor, and the Role of Medicaid," Health Affairs (1982).
11. These states include: Alabama, Colorado, Hawaii, Idaho, Indiana, Kansas, Kentucky, Louisiana, Nevada, New Hampshire, New Mexico, North Dakota, Rhode Island, South Dakota, Virginia, Washington State, West Virginia, Wisconsin, Wyoming.
12. Rosenbaum, Sara and Johnson, Kay, "Providing Health Care For Low Income Children: Reconciling Child Health Goals with Health Care Financing Realities," Milbank Quarterly (September, 1986).
13. Monheit, Alan, et. al., "The Employed Uninsured and the Role of Public Policy", National Center for Health Services Research, 1985.

14. Intergovernmental Health Policy Projects, State Programs of Assistance for the Medically Indigent (Washington, D.C., 1985).
- 14a. These states include Maryland, New Jersey, South Carolina, Massachusetts, West Virginia, New York, and Florida.
- 14b. IHPP, op. cit.
- 14c. These include Arkansas, Oklahoma, Texas and South Carolina.
15. The Act exempts the Medicaid, AFDC, WIC, Food Stamp and SSI programs for sequestration entirely and provides important protections for the Medicare and Community and Migrant Health Centers programs.
16. For example, in 1983, when the childhood poverty level passed the 13 million mark, state CCS agencies in 47 states served 620,000 of a million children, Public Health Agencies, 1983: Volume 3, Services for Mothers and Children (ASTHO Foundation, 1985).
- 16a. Ireys, Henry, et. al.,
17. This practice appears to be inconsistent with the federal Title V statute, which prohibits states from imposing charges on women with family incomes below 100% of the federal poverty level. 42 USC section 705(a) (5) (1982).
18. 42 USC section 703 (1982).
19. Institute of Medicine Preventing Low Birthweight (National Academy Press, Washington, D.C., 1985).
20. Ibid.
21. Prior to 1981, all Title V programs were required to maintain Children and Youth Projects, comprehensive pediatric clinics that furnished both "well child" and acute care. In 1981, this requirement was repealed. Pub. L. 97-35. A number of states have since eliminated their C&Y programs. Rosenbaum and Weitz, Children and Federal Health Care Cuts (CDF, Washington, D.C., 1983).
22. Sulvetta, op. cit.
23. Ibid.
24. Ibid.
25. Ibid.

26. Ibid.
27. e.g., Blendon, Robert, et. al., "Uncompensated Care by Hospitals or Public Insurance for the Poor: Does It Make a Difference?" 314 NEJM 1160 (May 1, 1986). Davis, Karen and Rowland, Diane, "Uninsured and Underserved," Securing Access to Health Care (President's Commission on Ethics in Medicine and Behavioral Research, Washington, D.C., 1983).

APPENDIX A

AFDC Maximum Payment Levels (and Medicaid Coverage) for Families
With No Other Income, 1986

State	Payment Level	As A Percent Of Poverty
Alabama	118.00	16.00
Alaska	740.00	78.00
Arizona	293.00	40.00
Arkansas	192.00	26.00
California	587.00	80.00
Colorado	346.00	47.00
Connecticut	569.00	77.00
Delaware	298.00	40.00
D.C.	327.00	44.00
Florida	252.00	34.00
Georgia	223.00	30.00
Hawaii	468.00	54.00
Idaho	304.00	41.00
Illinois	341.00	46.00
Indiana	256.00	35.00
Iowa	381.00	52.00
Kansas	394.00	53.00
Kentucky	197.00	27.00
Louisiana	190.00	26.00
Maine	389.00	53.00
Maryland	329.00	45.00
Massachusetts	432.00	59.00
Michigan	486.00	66.00
Minnesota	528.00	72.00
Mississippi	120.00	16.00
Missouri	274.00	37.00
Montana	354.00	48.00
Nebraska	350.00	47.00
Nevada	285.00	39.00
New Hampshire	389.00	53.00
New Jersey	404.00	55.00
New Mexico	258.00	35.00
New York	497.00	67.00
North Carolina	246.00	33.00
North Dakota	371.00	50.00
Ohio	302.00	41.00
Oklahoma	310.00	42.00
Oregon	397.00	54.00
Pennsylvania	382.00	52.00
Rhode Island	503.00	68.00
South Carolina	199.00	27.00
South Dakota	329.00	45.00
Tennessee	153.00	21.00

APPENDIX A
(continued)

State	Payment Level	As A Percent Of Poverty
Texas	184.00	25.00
Utah	376.00	51.00
Vermont	583.00	79.00
Virginia	354.00	48.00
Washington	492.00	67.00
West Virginia	249.00	34.00
Wisconsin	544.00	74.00
Wyoming	360.00	49.00

APPENDIX B
 OUTPATIENT MATERNITY PROGRAMS:
 PROGRAM ELIGIBILITY CRITERIA
 July, 1986

State	Income Standard	High Risk	Other
AL	<150% poverty	X	
AK	no eligibility	criteria	
AZ	<100% poverty		
AR	no eligibility	criteria	
CA	<200% poverty		
CO	<150% poverty	X	
CT	<185% poverty		
DE	free care: <100% pov. sliding scale: 100-250% poverty		
DC	free care: <95% poverty sliding scale: >100% poverty		
FL	<150% poverty		
GA	free care: <150% poverty sliding scale: >150% poverty	X	
HI	no eligibility	criteria	
ID	<150% poverty	X	
IL	<185% poverty		
IN	<150% poverty		
IA	<150% poverty		
KS	<150% poverty		
KY	varies		
LA	no eligibility	criteria	
ME	<172% poverty		
MD	varies		
MA	<185% poverty		

Appendix B
(continued)

State	County	Year	Range
42	Clark County		
43	Clark County	1	
44	Clark County: Clark County		
45	Clark County: Clark County		
46	Clark County		
47	Clark County	1	1
48	Clark County		
49	Clark County	1	1
50	Clark County		
51	Clark County		1
52	Clark County: Clark County		
53	Clark County: Clark County		
54	Clark County		
55	Clark County		
56	Clark County		
57	Clark County		
58	Clark County		
59	Clark County		
60	Clark County		
61	Clark County		
62	Clark County		
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91	Clark County		
92	Clark County		
93	Clark County		
94	Clark County		
95	Clark County		
96	Clark County		
97	Clark County		
98	Clark County		
99	Clark County		
100	Clark County		

Appendix B
(Concluded)

State	Income Standard	High Risk	Other
TX	<100% poverty	X	
UT	free care: <150% poverty sliding scale: >150% poverty		
VT	n o e l i g i b i l i t y	c r i t e r i a	
VA	<100% poverty	X	
WA	<150% poverty		
WV	<150% poverty		
WI	<150% poverty		Also, uninsured and unemployed
WY	---	---	---

APPENDIX C
OUTPATIENT MATERNITY PROGRAMS:
PROGRAM SCOPE*

State	Distribution of Services	Number Served	Estimated Need
AL	SW	1,000	U
AK	NSW	U	U
AZ	NSW	1,150	11/15 counties served
AR	SW	9,000	U
CA	SW	18,000	U
CO	NSW	2,700	2,700/4,178 served
CT	TA	3,000	3,000/5,000 served
DE	SW	700	700/3,000 served
DC	SW	U	U
FL	SW	45,000	45,000/66,000 served
GA (A)	TA	2,500	U
HI	NSW	U	U
ID	TA	600	U
IL (B)	TA	3,000+	U
IN	NSW	5,133	5,133/7,797 served
IA	NSW	2,000-3,000	60% served
KS	NSW	1,800	1,800/6,000 served
KY	NSW	9,400	50-60% served

KEY: SW= statewide
U= unknown

TA= targeted areas

NSW= not statewide

APPENDIX C
(Continued)

State	Distribution of Services	Number Served	Estimated Need
LA	SW	96,000	U
ME	SW	1,500	1,500/3,000 served
MD (C)	SW	8,644	8,664/13,885 served
MA	SW	10,500	all served
MI (E)	TA	5,500-6,000	U
MN	NSW	U	U
MS	SW	10,500	10,500/13,890 served
MO	NSW	5,200	U
MT	---	---	---
NB	TA	1,000	U
NV	---	---	---
NH	NSW	800	U
NJ (F)	NSW	10,555	10,555/27,000 served
NM	NSW	5,500	U
NY	NSW	17,000	17,000/30,000 served
NC	NSW	23,000	all 100 counties served
ND	NSW	100	U
OH	NSW	13,000	64/88 counties

Key: SW = statewide TA = targeted area NSW = not statewide

U = unknown

APPENDIX C
(Continued)

State	Distribution of Services	Number Served	Estimated Need
OK	NSW	6,000	40/77 counties served
OR	NSW	3,000 (including Medicaid deliveries)	U
PA	NSW	17,870	U
RI	SW	3,000	all served
SC	SW	7,500	7,500/9,500 served
SD	NSW	53	3 sites in 67 counties served
TN	NSW	14,000	14,000/16,000 served
TX	NSW	U	U
UT	TA	640	25% served
VT	TA	290	U
VA	TA	12,000	U
WA	TA	2,000	U
WV	NSW	4,500	65% served
WI (G)	NSW	U	U
WY	---	---	---

Key: SW = statewide TA = targeted areas NSW = not statewide
U = unknown

APPENDIX C
(Continued)

State Title V agencies that administer maternity services, including those that provide services on a statewide basis, may in fact not have sufficient resources to meet the needs of the target populations. With respect to maternity care, a number of states were able to provide estimates concerning the percentage of the target population their programs met. Virtually no state agencies, however, appear to have conducted similar estimates with respect to pediatric services.

In some cases, states' estimates were provided in terms of numbers of women served versus number requiring services. In others, percentages were provided. Additionally, many states that did not administer statewide maternity programs provided CDF with information on the number of unserved counties.

APPENDIX D
INPATIENT MATERNITY PROGRAMS:
July, 1986

State	Eligibility Criteria	Distribution Services	Number Served	Funding Sources
AL	---	---	---	---
AK	---	---	---	---
AZ	low income, uninsured	NSW	1,150	SA
AR	<130% poverty, high risk	TA	471	SA
CA	---	---	---	---
CO	<150% poverty, low risk	TA	1,900	SA
CT	---	---	---	---
DE	---	---	---	---
DC	---	---	---	---
FL	low income, high risk	TA	U	SA
GA(A)	high risk	TA	U	CO
HI	---	---	---	---
ID	---	---	---	---
IL(B)	high risk	SW	U	SA
IN	---	---	---	---
IA	---	---	---	---
KS	---	---	---	---
KY	<185% poverty, high risk	SW	U	BG,SA, local

Key: SW = statewide TA = targeted areas NSW = not statewide
 U = unknown BG = Block Grant SA = state appropriation
 CO = county

APPENDIX D
 (Continued)
 Distribution
 Services

State	Eligibility Criteria	Distribution Services	Number Served	Funding Sources
LA	none	SW	U	SA
ME	<172% poverty	SW	U	SA
MD(C)	---	---	---	---
MA(D)	<185% poverty, uninsured	SW	U	SA
MI(E)	---	---	---	---
MN	---	---	---	---
MS	<100% poverty, high risk	U	817	SA
MO	---	---	---	---
MT	---	---	---	---
NE	---	---	---	---
NV	---	---	---	---
NH	---	---	---	---
NJ(F)	---	---	---	---
NM	high risk	SW	100	BG
NY	uninsured, low income	NSW	1,400	SA
NC	<100% poverty	NSW	2,162	SA
ND	---	---	---	---
OH	---	---	---	---
OK	---	---	---	---
OR	none	SW	U	CO

Key: SW = statewide TA = targeted areas NSW = not statewide
 U = unknown BG = Block Grant SA = state appropriation
 CO = county

APPENDIX D
(Continued)

State	Eligibility Criteria	Distribution Services	Number Served	Funding Sources
PA	---	---	---	---
RI	---	---	---	---
SC	<150% poverty, high risk	TA	1,000	BG,SA
SD	low income, high risk	U	28	BG
TN	<125% poverty	NSW	U	BG,SA
TX	<100% poverty, high risk	NSW	U	SA
UT	---	---	---	---
VT	none	TA	290	BG,SA
VA	<200% poverty	TA	457	BG
WA	---	---	---	---
WV	<150% poverty	NSW	U	BG,SA
WI(G)	<150% poverty	TA	180	SA
WY	---	---	---	---

Key: SW = statewide TA = targeted areas NSW = not statewide
 U = unknown BG = Block Grant SA = state appropriation
 CO = county

APPENDIX D
(Continued)

- A) Georgia also requires county health departments to serve pregnant women as condition of grants from state. No uniform eligibility criteria. 30,000 women served.
- B) Illinois has two programs, including the "9/90" program and a problem pregnancy program.
- C) Maryland recently enacted a new prenatal care program for pregnant teens with family incomes below 100% federal poverty level.
- D) Massachusetts serves 5,000 in its Maternity and Infant Care (MIC) project and 5,500 under its Healthy Start Initiative.
- E) Michigan is in the process of expanding funding under its program to cover all uninsured women with family incomes below 185% of the federal poverty level.
- F) New Jersey is in the process of enacting a new maternity and infant care program that would provide outpatient care to pregnant women and children under 18 months whose family incomes are below 100% of the federal poverty level.
- G) The Wisconsin prenatal care program is exclusively a part of WisconCare, a state program for the unemployed and uninsured.

APPENDIX E
PEDIATRIC SERVICES FOR LOW INCOME CHILDREN
July, 1986

State	Comprehensive Primary Care (Outpatient)	Well-Child Care Only (Outpatient)	Acute Care (Outpatient)	Inpatient (1) Care
AL		X		
AK		X		
AZ		X		
AR				
CA		X		
CO		X		
CT		X	X*	
DE		X	X	
DC		X		
FL				
GA		X	X*	
HI				
ID				
IL		X		
IN		X		
IA	X			
KS		X		
KY		X		X
LA		X		X
ME		X		
MD		X		

*limited

(1) covers services after the newborn period and excluding programs for crippled children

APPENDIX E
(Continued)

State	Comprehensive Primary Care (Outpatient)	Well-Child Care Only (Outpatient)	Acute Care (Outpatient)	Inpatient (1) Care
MA	X			
MI		X		
MN		X		
MS		X		
MO		X		
MT		X		
NE	X			
NV				
NH		X		
NJ (A)	X*	X		
NM		X		
NY	X		X*	
NC		X	X*	
ND		X		
OH		X	X*	
OK	X			
OR		X		
PA		X		
RI	X		X*	
SC		X		X
SD		X		

*limited

(1) covers services after the
newborn period and excluding
programs for crippled children

APPENDIX E
(Continued)

State	Comprehensive Primary Care (Outpatient)	Well-Child Care Only (Outpatient)	Acute Care (Outpatient)	Inpatient (1) Care
TN		X		
TX		X	X*	
UT		X	X*	
VT		X		
VA		X	X*	
WA		X		
WV		X	X*	
WI		X		
WY		X		

*limited

(1) covers services after the
newborn period and excluding
programs for crippled children

A New Jersey is in the process of enacting a maternity and infant care program that would provide comprehensive outpatient services to uninsured pregnant women and children under 18 months of age with family income below 100% of the federal poverty level.

APPENDIX F
OUTPATIENT PSYCHIATRIC SERVICES
PROGRAM SCOPE
1986

State	Distribution of Services	Number Served	Eligibility Criteria
AL	DP	16,000*	< 1000 per < 2 years
AK	DD	no service	DD
AZ	DD	no service	< 1000 per < 2 years
AR	---	---	---
CA	DP	0	< 2000 per
CO	DD	0	< 1000 per < 15 years
CT	TA	1,000	< 2 years
DE	DP	14,000	DD (DP)
DC	DP	9,714 service	< 500 per
FL	---	---	---
GA	DP	100,000*	DD
HI	---	---	---
ID	---	---	---
IL	---	---	---
IN	DD	10,000	< 1000 per
IA	DP	0	< 1000 per
KS	DD	0	DD (DP)
KY	DP	12,000	< 1000 < 6 years
LA	DP	121,000*	DD

DD: DP+ statewide
DP+ statewide
attaches

TA+ targeted areas

DD+ not applicable

APPENDIX 10
Continued

STATION	STATION NAME	STATION NAME	STATION NAME
100	1000	10,000	10,000,000
101	101	101,000	101
102	102,000	102,000	102
103	103	10	10,000,000
104	104,000,000	104,000,000	104
105	105	105,000	105
106	106	10	100,000
107	107	10	100,000
108	108	108,000,000,000	108,000,000,000
109	109	109	109
110	110	11,000	11,000,000
111	111	11	11,000,000 110,000,000,000
112	112	112,000	112
113	113	113,000,000,000	113,000,000,000 113,000,000
114	114	11	11,000,000
115	115	115,000	115
116	116	116,000,000,000	116,000,000
117	117	117,000	117,000
118	118,000,000	118	118,000,000

1000-1000 10,000,000 101 101,000,000 102 102,000,000,000
103 103,000,000

APPENDIX C

STATES THAT CONTRIBUTE STATE FUNDS
TO PROVIDE HEALTH CARE TO LOW INCOME,
UNINSURED PREGNANT WOMEN AND CHILDREN
July, 1986

State	Outpatient Maternity	Inpatient Maternity	Outpatient Pediatric	Inpatient Pediatric
AL				
AK				
AZ	X	X		
AR	X	X		
CA	X		X	
CO	X	X	X	
CT	X			
DE	X		X	
DC	X			
FL	X	X		
GA	X		X	
HI	X			
ID	X			
IL	X	X		
IN				
IA	X		X	
KS	X			
KY	X	X	X	X
LA	X	X	X	X
ME	X	X		
MD	X			
MA	X	X	X	

APPENDIX G

STATES THAT CONTRIBUTE STATE FUNDS
TO PROVIDE HEALTH CARE TO LOW INCOME,
UNINSURED PREGNANT WOMEN AND CHILDREN
July, 1986

State	Outpatient Maternity	Inpatient Maternity	Outpatient Pediatric	Inpatient Pediatric
AL				
AK				
AZ	X	X		
AR	X	X		
CA	X		X	
CO	X	X	X	
CT	X			
DE	X		X	
DC	X			
FL	X	X		
GA	X		X	
HI	X			
ID	X			
IL	X	X		
IN				
IA	X		X	
KS	X			
KY	X	X	X	X
LA	X	X	X	X
ME	X	X		
MD	X			
MA	X	X	X	

APPENDIX G
(Continued)

State	Outpatient Maternity	Inpatient Maternity	Outpatient Pediatric	Inpatient Pediatric
MI	X		X	
MN	X			
MS	X	X	X	
MO	X			
MT				
NV				
NH	X		X	
NJ	X			
NM	X			
NY	X	X	X	
NC	X	X	X	
ND				
OH	X		X	
OK	X		X	
OR	X		U	
PA	X		X	
RI	X		X	
SC	X	X		
SD				
TN	X	X	X	
TX	X	X		
UT				
VT	X	X	X	

APPENDIX G
(Continued)

State	Outpatient Maternity	Inpatient Maternity	Outpatient Pediatric	Inpatient Pediatric
VA	X		X	
WA			X	
WV	X	X	X	
WI	X			
WY			X	

APPENDIX H

BARRIERS TO HOSPITAL CARE
 REPORTED BY STATE MCH AGENCIES
 July, 1986

State	Reports of people denied or turned away from services because of an inability to pay?	Are preadmission deposits required for inpatient care?
AL	WC,OB,AL	unknown
AK	PR	unknown
AZ	none	yes: obstetrical patients
AR	OB	unknown
CA	PD	unknown
CO	CH,OB	yes: obstetrical patients
CT	AL	unknown
DE	none	no
DC	PD	unknown
FL	unknown	no answer
GA	OB,AL	no answer
HI	none	no
ID	PR	yes
IL	WC,OB,AL,PD	yes
IN	unknown	unknown

Key: WC = denied well child care
 PR = denied prenatal care services
 OB = denied admission to hospital for delivery
 AL = denied admission to hospital for delivery if not
 in active labor
 PD = reports of patients turned away from care and told
 to seek care at another hospital may or may not
 include pregnant women and children
 CH = child denied admission to hospital for care

APPENDIX H
(Continued)

State	Reports of people denied or turned away from services because of an inability to pay?	Are preadmission deposits required for inpatient care?
IA	OB	no answer
KS	none	yes: obstetrical patients
KY	PD	yes: obstetrical patients
LA	all uninsured patients must go to "charity" hospitals	no answer
ME	none	no
MD	AL	unknown
MA	OB	unknown
MI	PD	unknown
MN	none	unknown
MS	CH	yes
MO	OB, PR	yes
MT	AL	unknown
NB	OB, AL	unknown
NV	none	unknown
NH	OB	unknown

Key: WC = denied well child care
 PR = denied prenatal care services
 OB = denied admission to hospital for delivery
 AL = denied admission to hospital for delivery if not
 in active labor
 PD = reports of patients turned away from care and told
 to seek care at another hospital may or may not
 include pregnant women and children
 CH = child denied admission to hospital for care

* when service limits are met.

APPENDIX H
(Continued)

State	Reports of people denied or turned away from services because of an inability to pay?	Are preadmission deposits required for inpatient care?
NJ	PD*	yes: obstetrical patients
NM	PR,OB	yes: obstetrical patients
NY	none	yes: obstetrical patients
NC	unknown	yes: obstetrical patients
ND	none	unknown
OH	OB,AL,PD	yes: obstetrical patients
OK	PR,PD	yes: obstetrical patients
OR	AL	yes: obstetrical patients
PA	AL	yes: obstetrical patients
RI	none	unknown
SC	unknown	yes: obstetrical patients
SD	none	yes: obstetrical patients
TN	none	yes: obstetrical patients

Key: WC • denied well child care
 PR • denied prenatal care services
 OB • denied admission to hospital for delivery
 AL • denied admission to hospital for delivery if not
 in active labor
 PD • reports of patients turned away from care and told
 to seek care at another hospital may or may not
 include pregnant women and children
 CH • child denied admission to hospital for care

APPENDIX H
(Continued)

State	Reports of people denied or turned away from services because of an inability to pay?	Are preadmission deposits required for inpatient care?
TX	OB,AL	yes: obstetrical patients
UT	AL	unknown
VT	none	unknown
VA	none	yes
WA	OB,AL,CH	yes
WV	OB	yes: obstetrical patients
WI	none, but counties have service limits	no
WY	PR	unknown

Key: WC = denied well child care

PR = denied prenatal care services

OB = denied admission to hospital for delivery

AL = denied admission to hospital for delivery if not
in active laborPD = reports of patients turned away from care and told
to seek care at another hospital may or may not
include pregnant women and children

CH = child denied admission to hospital for care

APPENDIX I

Effects of Green/Budenz on Title V Agencies
July, 1966

State	Were services cut as a result of the 1st round of Green/Budenz?		Has the state shown a willingness to replace federal money lost under Green/Budenz?		If there is a 2nd round of Green/Budenz cuts, how will the RCM program absorb the losses?
	Yes	No	Yes	No	
Alabama	✓			✓	✓ Across the board (in areas listed)
Alaska	✓			No answer	✓ Layoffs will occur
Arizona		✓	✓		✓ Disabled Children Program will end
Arkansas	✓		✓		✓
California	✓	ended down dental & child safety program			✓
Colorado	✓			✓	✓
Connecticut		✓			Preparing formula funding out of 283 not yet specified
Delaware		✓		✓	vs program funding gone, because they relied on carryover individual pro-grams could be eliminated
D. C.		✓	✓		there will be reduction providers
Florida		✓	No answer		not yet specified
Georgia		✓	✓		not yet specified

APPENDIX I
(Continued)

	Were services cut as a re- sult of the 1st round of Green/ Buden?		Has the state shown a willingness to replace federal money lost under Green/Buden?		If there is a 2nd round of Green/Buden cuts, how will the RCH program absorb the losses?
	Yes	No	Yes	No	
Neenit		✓		✓	CAV and NIC projects
Idaho	cut leg. hosp. for CCR to \$16,000/ case			✓	hosp. for high-risk mothers
Illinois		✓		✓	prenatal care expenditures will be limited
Indiana	✓			✓	- unknown -
Iowa	✓			✓	✓
Kansas		✓		✓	not yet specified
Kentucky		✓		✓	not yet specified
Louisiana		✓		unknown	services for older children
Maine		✓		unknown	
Maryland		✓		✓	not yet specified
Massachusetts		✓	✓		- unknown -

APPENDIX I
(Continued)

	Were services cut as a re- sult of the 1st round of Broom/ Bushman?		Has the state shown a willingness to replace federal money that could Broom/Bushman?		If there is a 2nd round of Broom/Bushman vote, how will the BCB program absorb the losses?	
	Yes	No	Yes	No	Across the board	Cuts to spend- ing areas (list)
Michigan	Family planning program					1) \$122 fever maternity patients 2) discontinu- ed Medicaid outreach 3) 11,000 fever family planning patients
Minnesota						
Mississippi	outreach, home visits					
Missouri						
Montana						
Nebraska	Univ. maternity program closed					

- u n n o v n -

not yet specified
CCB reduction

APPENDIX I
(Cont. listed)

	Have services met as a result of the 1st round of Gross/Budman?		Has the date when a willingness to replace Federal money limit under Gross/Budman?		If there is a 2nd round of Gross/Budman, how will the RCD program absorb the increase?	
	Yes	No	Yes	No	Across the board	Cuts in expenditures
Bevins						Cuts in RCD
Gov. Thompson						administration first then services
Gov. Jernigan						not yet specified
Gov. Nathan						prohibit, university will-child
Gov. Nash						
B. Caperton						family planning
B. Haskins						income & estate
Chiles						not yet specified
Chickens						not yet specified
Chisum						will-child care
Chisum services						general education, local planning, C&T activities, \$100 per person

APPENDIX 2
(Continued)

	Have objectives met up to 1970? Yes or No? (Number)		Have the objectives been accomplished by 1970? Yes or No? (Number)		Is there a total record of the objectives? Yes or No? (Number)	
	Yes	No	Yes	No	Yes	No
Health Services						
A. Diseases						
1. Tuberculosis						
2. Malaria						
3. Cholera						
4. Typhoid						
5. Dysentery						
6. Leprosy						
7. Syphilis						
8. Gonorrhea						
9. Venereal diseases						
10. Other						
11. Total						
12. Total						
13. Total						
14. Total						
15. Total						
16. Total						
17. Total						
18. Total						
19. Total						
20. Total						
21. Total						
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The Chairman: Thank you. I will ask my colleagues if they have any questions.

The *Chronicle* said, "I want to know how good your month has been. Have you gotten with us in an unusually important position? I know, having covered the full century, the year is a good deal of interest to those who will be happy and useful to us in the next year and month."

We are going to see national good coverage in the coming 12 months of subjects that we have covered in the evening. There are related to the ethnic question of health care is different way. The HIV problem, we will be doing a very important hearing on that next week. Some of the implications of environment as well as looking at more closely. We are going to find out that with the creation of new jobs, the end of one of them and jobs are being created at less than the private level, with all the implications that has to have of health coverage and the way to deal with that together.

While the American people have to live in health care in this town are 17 million Americans who have no coverage whatsoever. The last census in this town are 11 to 15 with significant health insurance. So 1 to 15 to 15 million Americans with some or no health insurance who are vulnerable in the health of America. And we have heard from people that the insurance

We find that the Greek is the question of their presence will influence some from families that are not all around other than themselves. This is something for the future, though there is no doubt that they are not people that are better in position going along the line with them. There are good-looking, smart, intelligent men and women and children who belong to the American West and the hope of the American West is not that they are living it down with intelligence and courage and with resources and why it should be moved and a different one more than in.

The concept of education should also involve in the economic sphere in a broad way. We in this country are experiencing a failure in education in that with that 12 or 13,000,000 of our children, 12 or 13,000,000, that are capable in the ability to get along in the world in the work. We will be collaborating with our colleagues in the economic sphere in the introduction of that and other means to get that to the best of our power that concept in the program.

The authors are still confronted with contradictory results: while 11 strongly conservative but also conservative women with 1 or 20 years in the firm is better at doing general tasks, the rest are in line with the other women (the average group is the 10-20 years), a something that we have to be sensitive to. I think that the issue of the savings for women is conservative and the conservative are at least that, especially in a way that suggests a series of other observations.

The focus for progress in the area of judicial reform is one of the most important areas facing the state. Although I think that Galtieri gives us some interesting insights, as well as others, the hearing is bereft of other work by that well-known and good attention, particularly the issue of reform and the use of that.

other areas as well. I understand in Alzheimer's disease there are some important areas of potential progress that offer very important hope for American people and, correspondingly, perhaps, some reductions in terms of the financial expenditures that will be necessary. That is something which is important to note.

Obviously, there are enormous possibilities now that we cannot turn our back on. We are mindful that in the President's request for reductions in nonmedical research are to be distressing. And I hope that proposal will be rejected by the Congress. I believe it will be for the reasons that Dr. Lederberg and others have spoken of, the enormous need for the investment, the incredible potential for progress.

Well, it seems to me that this whole health care area is a challenge for us at the national level; it is a challenge for state and local government; it is a challenge for families; it is a challenge for the private sector. And we have had some interesting testimony and proposals of what can be done from the private sector. All of us have to try and find ways in which we can exercise leadership. We have limits on the resources which are available, but it does seem to me that if we fulfill our responsibilities and meet this challenge, we can have a healthier and a more hopeful society, for young and old alike.

That is the challenge that is before us now, before this Committee and before the Congress. I welcome that challenge, and I look forward to working with our colleagues to see if we cannot make that challenge result in better health care for millions of families in this country.

We want to thank our panel very much. I would like to, if I could, keep the record open for some additional questions that I know Senator Hatch and perhaps others have. We do not want to unduly burden all of you, but I know that there will be some additional questions which will come out.

[Additional material supplied for the record follows:]



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DEAN

TUSKEGEE INSTITUTE SCHOOL OF VETERINARY MEDICINE

AND

PRESIDENT
THE ASSOCIATION OF MINORITY HEALTH PROFESSIONS
SCHOOLS

PRESENTED TO

COMMITTEE ON LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

CONCERNING

NATIONAL HEALTH GOALS

JANUARY 12, 1987

Mr. Chairman and Members of the Committee, thank you for the opportunity to offer our suggestions for critical priorities and goals that should be addressed in formulating national health policy. The Association of Minority Health Professions Schools is deeply concerned with the problem of inadequate or, in many cases, inaccessible health care for our nation's poor and minority citizens. We believe that many Americans are unaware of the vast dimensions of this problem. To us, there seems to be no other explanation for why so many citizens who have so much to contribute to our society, should be living their lives without adequate medical care.

Amongst us, each institution has first-hand knowledge of the desperate national situation that exists in this country's ability and willingness to provide access to basic health services for the nation's many, many poor and minority citizens and families who reside in medically under-served inner-city and rural areas. We speak for those who do not have the financial means to seek the right of good health and longevity. Those of whom we speak are not just the indigent and homeless who roam our city streets. We speak also of the over 35 million in our country who are unemployed or temporarily unemployed, those without medical insurance, those who are discriminated against, those who have little or no money, and those who live in areas where there are inadequate medical services and/or too

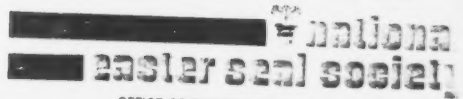
few providers located nearby.

At a 1986 National Conference on Health Care for the Poor, held at Meharry Medical College in Tennessee, it was noted that there is a widening gap in health status among the nation's poor and minorities and the nation's majority population. Also, in August of 1985, a Task Force appointed by the Secretary of the Department of Health and Human Services reported a significant gap in health status among the nation's blacks and other minorities when compared to the nation's white population. Black infants are twice as likely to die in their first year of life than are white infants. The life expectancy of blacks is five years less than that of whites. The Secretary's Task Force reported that annually, in the black community, almost 60,000 excess deaths occur because of the disparity in health status. Evidence presented by both of these efforts also indicates that the problem is growing, not getting better. Unfortunately, the Administration has consistently proposed to eliminate or severely cut a broad range of the federal programs which provide assistance to the poor and minority populations of the country.

Mr. Chairman, as you know, our Association has appeared before this Committee, in previous years, to discuss the importance of health professions and biomedical research programs authorized by your Committee. It is documented that black health professionals are more likely to locate their practices in under-served minority areas. This alone makes the case for continued emphasis on federal health professions training support

for minority institutions and the students who attend these institutions. Further, there should be an establishment of Centers of Research and Training Excellence at minority institutions for the purpose of researching those diseases and illnesses that are more common to Blacks, and for training of young clinicians, investigators, and scholars. These two small initiatives, we believe, will have a significant positive impact upon the continued problem of poor access to health care for minority and poor persons who live in under-served areas.

Mr. Chairman, thank you for the opportunity to present the views of the Association of Minority Health Professions Schools. We will assist you, in any way we can, to close this widening gap in health status.



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JOSEPH D. ROMER
DIRECTOR

STATEMENT OF

STEVEN FEINBERG, M.D.

Medical Director,
North Fulton County Hospital
Roswell, Georgia

on behalf of

**The National Association of Rehabilitation Facilities
The American Occupational Therapy Association
and the
National Easter Seal Society**

before

**The Private/Public Sector Advisory Committee
on Catastrophic Illness**

June 20, 1986

Mr. Chairman and Members of the Committee:

I am Dr. Steven Feinberg, Medical Director of North Fulton County Hospital in Roswell, Georgia. I am appearing before the committee today on behalf of the National Association of Rehabilitation Facilities (NARF) of which I am a member of the Board of Directors. I am also speaking on behalf of the American Occupational Therapy Association (AOTA) and the National Easter Seal Society (NESS).

NARF is the national voluntary organization of community based rehabilitation facilities. Its membership includes over 600 facilities including freestanding rehabilitation hospitals, rehabilitation units in general hospitals, outpatient rehabilitation facilities and vocational developmental centers. They serve over 700,000 persons with disabilities annually.

AOTA is the professional association representing over 40,000 occupational therapists nationwide. NESS represents over 100 local Easter Seal Societies offering medical vocational and other rehabilitation services.

The objective of medical rehabilitation is to restore people who suffer from illnesses, injuries or congenital deformities to their maximum functional level. A recent study by NARF revealed that the average length of stay in these facilities is 34.1 days and the average charge per case exceeds \$15,000 with charges

ranging considerably higher for certain injuries. These figures reflect only inpatient medical rehabilitation costs. These costs are catastrophic for any individual or any family with a member who suffers from a stroke, brain injury, spinal cord injury, various forms of arthritis, congenital deformities and other major traumas. Over 80 percent of the people sent to rehabilitation hospitals and units return home. Only 17 percent are referred to skilled nursing facilities. Rehabilitation services include physician services, rehabilitation nursing services, physical, occupational, speech language pathology and audiology services, psychological and social services, recreation therapy services as well as equipment and supplies.

Many rehabilitation patients require extensive outpatient rehabilitation services delivered by either freestanding outpatient facilities, home health agencies, hospital outpatient departments and rehabilitation agencies.

We commend this committee for addressing the tremendous costs associated with a serious illness or injury and for exploring various mechanisms to meet these expenses. We also commend the Secretary for establishing the working group to look into the issue of long term care. We urge the committee, in its consideration of any final proposals to the Secretary, to look at the need for catastrophic health insurance which addresses both inpatient and outpatient medical rehabilitation needs for the total population - the employed, unemployed, underemployed, the

poor and the Medicare population. We also recommend that you include long term care insurance in any final recommendation. We make this statement in view of all our facilities' and professional experience with the catastrophic and long term care needs of rehabilitation patients whether the services are delivered at home or in an institution.

Catastrophic insurance is generally defined as coverage for large health care expenses, usually measured annually and caused by the onset of a serious chronic illness or an accident resulting in recurring, costly treatment and, frequently, repeated hospital admissions.

The committee has, I believe, already heard extensive testimony about why existing health coverage does not adequately address the needs of many patients. The problems in Medicare, Medicaid and commercial health insurance highlighted in previous testimony are magnified 100 fold when focused on a patient needing rehabilitation services. There are glaring gaps in coverage and payment for patients needing rehabilitation services and disabled individuals with residual impairments who incur continuing costs for medical, health and personal care needs.

Most Americans have some form of health insurance. However, it may be limited by maximum dollar expenditures and/or the scope of covered services. Medicare and Internal Revenue tax subsidies help pay for these extraordinary expenses, however, there are, as this committee has heard, over thirty-five (35) million Americans

who have no or limited health care insurance. There are also thirty-six (36) million Americans with disabilities. Of this group approximately one third do work and receive no public assistance. One quarter are receiving public assistance but are not working. The balance receive public assistance and 5 percent of them work. However, the nature and extent of their health care coverage is not well known.

Studies show that half of those who spend more than \$5,000 per year for medical expenses are in institutions. 1.3 percent of the population accounts for more than 50 percent of all charges in short stay hospitals, and this pattern holds across all age groups. If data on long stay institutions is added, approximately 2 percent of the population accounts for over 60 percent of hospital and institutional care expenses each year. High family costs tend to be concentrated on one family member. Also, high cost illnesses are repetitive and result in repeated hospitalizations, and, these costs began before and continue after the year measured in the studies. Disabled Medicare beneficiaries use nearly twice as many Medicare services as the elderly and use them more at every expenditure threshold.

The most recent study from the National Center for Health Care Statistics show that

a fifth of the nation's 80 million families incur 'catastrophic' out-of-pocket medical expenses--costs that absorb an abnormally high percentage of their total income. Nearly 16 million families spend 5 percent or more of their annual incomes on out-of-pocket medical costs, even though these expenses average under \$500 a year in nearly a third

of the cases... Half spend 10 percent of their earnings on medical care, and over 3 million families use at least 20 percent for the same purpose. Hospital care is the biggest expense for the 16 million families with large medical bills. Nearly half of the money by families in the 10 percent bracket, for example, goes toward hospital inpatient services--nearly twice as much as for families as a whole.

While some of the 16 million families incur catastrophically high expenses in spite of fairly comprehensive insurance coverage, most face a combination of little or no insurance coverage and low income. In fact, two-thirds of families with high out-of-pocket medical expenses have incomes below the federally set poverty line. Many of these families are headed by an unemployed person under 18 or over 65 years of age. Among those with some public or private insurance, coverage varies according to the ratio of direct expenses to costs of families in the 5 percent expenditure bracket, but covers 28 percent of the total costs for those in the 20 percent category. Conversely, the share paid by Medicaid and private insurance declines as out-of-pocket expenditures rise in relation to income.

Besides spending a large portion of their income on medical care, families with high out-of-pocket costs account for a disproportionate share of the health care expenditures of U.S. families as a whole. For example, families in the 5 percent expenditure bracket account for more than 40 percent of all health care expenditures; those in the 10 percent group are responsible for a quarter; and families in the 20 percent expenditure group account for 13 percent.

Our members have found that rehabilitation patients easily exhaust their health care coverage or require extensive services which are not covered. In either event the patient and the family, if a family support system exists, are confronted with excessive financial burdens for the services. If the patient is unable to pay, our facilities must decide under what conditions to provide the services. Many non-profit facilities are required by their charters to serve patients without regard to their ability to pay which may cause excessive financial burdens for a facility.

A brief study of insurance coverage by NARF has revealed that rehabilitation services needed by patients depends upon whether a patient is hospitalized, since nonhospital custodial or skilled nursing home care or extensive home health care is frequently not covered except under Medicaid and partially covered under Medicare. This limited coverage, which is dependent upon hospital stays, does not address chronic illnesses or disabilities which require intermittent hospitalization and home health or nursing care.

Additionally this study highlighted the problems that exist under commercial health insurance with coverage for rehabilitation services. Last week the Washington Post carried a four part series on the experience of a Virginia family when their 20 year old son was in an automobile accident and suffered severe head injuries. This article traced his care from the shock/trauma center through his rehabilitation. The excellent series highlighted all the emotion, time and money which a family experiences when a member suffers a catastrophic illness.

The second article in the series highlighted the problems the family faced when he was ready for rehabilitation. When the family sought to have him moved to a rehabilitation unit in a local hospital, (which is a NARF member) they discovered that their health care coverage through the federal government, a health maintenance organization (HMO), Kaiser Permanente did not cover rehabilitation services. The article notes that the son

had been in a trauma center hospital for 78 days before being transferred. According to NARF's recent study the range and length of stay once a patient is referred for rehabilitation services for a head injury is from 12 to 80 or more days. Again, this is only for the inpatient hospital rehabilitation stay and does not account for the services needed after discharge from the hospital.

With respect to this particular case the bills were infinitely higher. The shock/trauma charges alone were over \$100,000. The family had never worried about bills before, assuming that the medical insurance through the father's employment covered all possibilities. The family, like many families, had no reason to believe that they would find themselves without coverage. Once the son began to emerge from a coma and qualified for a rehabilitation center, Kaiser Permanente first stated it would pay none of the cost, estimated at \$18,000 per month, for rehabilitation at a rehabilitation center near their home. The family, upon reviewing the benefit booklet which had been supplied, found at the very end of the list of exclusions under "What Is Not Covered" an exclusion for "the services of a rehabilitation center." These types of exclusions are not uncommon in commercial insurance coverage and are particularly common with HMOs. Frequently, a company will say that the services of a rehabilitation hospital are not covered because the hospital does not meet the plan's definition of a hospital, usually because it requires surgical facilities on the premises and does not recognize a contractual arrangement with another

local facility. A second frequent type of exclusion, cited in the article is that the insurance does not cover care which is primarily for rehabilitation, convalescence or custodial care. However, this particular health plan would cover 100 days a year if the son were in a nursing home as opposed to a rehabilitation center. The family's only other option was to qualify for Medicaid but the only state approved Medicaid facilities were 100 miles away in Boston.

After a second opinion and repeated interviews the HMO agreed to pay for four more weeks of care in a general hospital while the son received speech and physical therapy. It still would not promise to pay for long term rehabilitation once the son left the hospital. Eventually it agreed to pay for only 60 days of rehabilitation care in the rehabilitation unit of the local hospital.

When interviewed, the company stated that it tries to predict how many catastrophic bills it may incur and, while it may be willing to absorb "our fair share of cases like this," it did not want to price its product out of the market and suggested that families obtain major medical policies for an additional monthly premium. The Post noted that major medical policies can be difficult to obtain and that Kaiser and most HMOs simply do not offer them.

Almost a year after the injury, the son continues to make progress in the rehabilitation unit. After intervention by the

government, the hospital was qualified by the state to treat Medicaid recipients. One wonders why obtaining coverage had to be so difficult!

Existing coverage has a high institutional bias. If services are to be received, they are generally available only when a patient remains in a hospital setting. Hence, there is often inappropriate institutionalization and unnecessary care for some patients, and inadequate or unavailable services for others. After hospitalization, a patient is frequently referred for outpatient services, home health care or skilled nursing care. When a patient's coverage is exhausted or the needs less intense services which are not covered such as nonskilled services, simple custodial care, respite care or home health aid care, these services are withheld. The patient's health may decline demanding readmission to a hospital and the cycle begins anew. So do the costs. These problems are becoming increasingly acute as our nation ages and as medical technology saves more people, but leaves impairments requiring extensive rehabilitation services. Those over age 65 will comprise 17.3 percent of the population by 2020; those over 65, 2.4 percent.

The objective of medical rehabilitation is achieved through integration of medical and social services. As noted, the types of injuries and illnesses which are treated by rehabilitation medicine include spinal cord injuries, stroke, head injuries, amputations, soft tissue injuries, arthritis, major fractures and others. Hospitals specializing in rehabilitation medicine and

treatment developed from early models such as the Institute of Physical Medicine and Rehabilitation in New York. There are slightly over 500 rehabilitation hospitals and units throughout the country. They are licensed by the states where they are located and accredited by the Joint Commission on Accreditation of Hospitals or the Commission on Accreditation of Rehabilitation Facilities. They also qualify under the Medicare Act as hospitals. There are over 600 outpatient facilities offering some level of rehabilitation services.

The primary function of such facilities is to provide diagnosis and treatment of patients for specified medical conditions both surgical and nonsurgical. The characteristics of freestanding hospitals and rehabilitation units differ little from those of acute care hospitals except their services are focused on fewer treatment areas. The average length of stay is longer because the objective is restoration of impaired functions which generally follow serious disease or injury. Once a patient is released, many require outpatient and home care services. Some disabled people require continuing institutionalization when home and community care is inadequate.

While the emotional benefit of personal independence may not be measured in dollars, psychological, physical and financial independence can. Recent studies of rehabilitation patients who are medically and vocationally rehabilitated show that for every federal dollar invested the person's earnings increases \$18 per

hour. Cost studies of stroke rehabilitation also show considerable return on the investment in services. A person who is not rehabilitated costs \$92,736 in 1980 dollars more to support than a rehabilitated patient living at home. The average cost for a stroke rehabilitation program is \$8,000-\$11,500 in 1980 dollars. This results in average savings of \$81,250 to \$84,740, again in 1980 dollars.

In view of the problems of coverage and payment of rehabilitation services, our organizations recommend the following to the committee:

A. COVERAGE

Any final proposal from the committee should recognize and cover rehabilitation and the complete spectrum of the patient's rehabilitation and long term care needs. Catastrophic costs are a continuing fact for the rehabilitation patient, the family and others, particularly those with long term disabilities. The challenge is real and solutions must be realistic. Any policy definitely should have catastrophic health insurance as an addition to or replacement for existing benefits, not as a trade-off for or limitation on other benefits which may further burden a majority while benefiting only a few.

B. POPULATIONS

Any final recommendation from the committee should cover all populations including the poor, working poor, unemployed, employed, and Medicare and Medicaid beneficiaries through a

combination of governmental programs, complementary private sector insurance and tax incentives for individuals incurring rehabilitation expenses.

C. CONTINUUM OF CARE SETTINGS

Any final recommendations should recognize that services are delivered in alternate settings reflecting the continuum of rehabilitation care and should be covered for payment. These include rehabilitation units of general hospitals, freestanding medical rehabilitation units, hospital outpatient departments, comprehensive outpatient rehabilitation facilities, rehabilitation agencies, skilled nursing facilities and the home. Delivery of services at or while at home as opposed to continued institutionalized care should be emphasized, except when not medically advisable.

D. SERVICES

Coverage of services offered under Part A and B of Medicare is a starting point for a basic package of rehabilitation services. In addition it should provide for the long term care needs of rehabilitation patients by expanding services such as unlimited home health, outpatient rehabilitation, respite, adult day, home health aide and psychosocial rehabilitation services. Existing exclusions in commercial insurance for rehabilitation services or rehabilitation sites should be eliminated.

E. FINANCIAL THRESHOLD

Any proposal for catastrophic health insurance should include a deductible amount as a percentage of income or period which is not based on an absolute annual expenditure. The deductible could be based on a family's out-of-pocket health expenses over three years. We make this recommendation in view of the numbers of rehabilitation patients and persons with disabilities who incur a high amount of medical expenses over several years.

Alternately, a spell of illness type of accounting could be used. Under this system, after a person met a deductible amount he or she would not have to pay it again the next year if the medical costs were the same as or related to the same cause or spell of illness. A spell of illness could be considered over when out-of-pocket health expenses do not exceed \$600.00 during a 9 month period.

F. FINANCING

Our organizations are aware that a major concern of the committee is how to finance any final proposal. We recommend that the committee examine restructuring the Medicare program by considering payroll taxes, premiums, deductibles and coinsurance as possible income sources. The committee may consider arraying these proposals against various income levels.

With respect to the nonMedicare and nonMedicaid population, We recommend that the committee look at tax incentives for employers offering catastrophic and long term care health insurance with

premiums shared with employees, some form of insurance shared by federal and state governments and providers for the unemployed and underemployed and the concept of a medical IRA or expanding the amount allowed for existing IRAs.

One objective of these alternatives is assuring that nonpoor, low and middle income families do not have to exhaust all of their resources and qualify for Medicaid. Medicaid should remain as the assurance of health care coverage for the poor.

While not participating in the preparation and presentation of this statement, the International Association of Psychosocial Rehabilitation Services (IAPSRs) has reviewed and is in general support of the final recommendations.

IAPSRs is an association representing over 150 community-based rehabilitation agencies in the United States serving adults with psychiatric disabilities.

We are prepared to work with the committee as it grapples with these difficult issues.

STATEMENT OF

PEGGY MUETTERTIES, EXECUTIVE DIRECTOR
JAYNE SHOVER EASTER SEAL REHABILITATION CENTER, INC.

on behalf of

THE ILLINOIS EASTER SEAL SOCIETY, INC.

and the

JAYNE SHOVER EASTER SEAL REHABILITATION CENTER, INC.

before

THE PRIVATE/PUBLIC SECTOR ADVISORY COMMITTEE

on

CATASTROPHIC ILLNESS

July 30, 1986

Mr. Chairman and Members of the Committee:

I am Peggy Muetterties, Executive Director of the Jayne Shover Easter Seal Rehabilitation Center in Elgin, Illinois. I am appearing before the committee today on behalf of the Illinois Easter Seal Society, Inc. and the Jayne Shover Easter Seal Rehabilitation Center, Inc.

The Illinois Easter Seal Society was organized in 1935 as an affiliate of the National Easter Seal Society. There are 23 local chapters in the State of Illinois affiliated with the Illinois Easter Seal Society that provide a multiplicity of direct and indirect services to disabled children and adults.

The Jayne Shover Easter Seal Rehabilitation Center is one of the 23 local chapters in Illinois. The Center is a free standing, out-patient, rehabilitation center that has provided comprehensive rehabilitation services to disabled children and adults for the past 34 years.

My testimony is to urge the committee to take into account the needs of people with disabilities, and the value of rehabilitation services when there is discussion of administrative or legislative remedies regarding the cost of catastrophic illness. From an Easter Seal perspective these points are central to the development of a catastrophic coverage plan.

Our local newspaper recently ran a story about an 18 year old woman who was on her way to classes at the local community college. Her car hit a rain-soaked patch of road, skidded and flipped over on its roof. She was pinned underneath the car and had to be freed by rescue workers. They told her at a rehabilitation hospital in Chicago that she would never walk again. She spent 75 days at the rehabilitation hospital learning how to sit-up again, how to move about and how to use a wheelchair. Technically a quadriplegic, she has gradually regained limited use of her arms and hands, although she does not have enough strength in them to do fine-motor activities such as, operating a curling

iron. She is at home now, where she receives physical and occupational therapies that are teaching her to get in and out of bed, how to enter a car, how to maneuver her wheelchair across different surfaces, how to become adept at getting along in a mobile society. Her body's temperature regulator doesn't work correctly anymore, so she has to take medication to prevent her from perspiring too much. She also takes medication to prevent muscle spasms in her legs. She wants to put her shattered life together and return to school, but before she can manage this there is the problem of transportation.

This true story of an 18 year old woman, with her whole life ahead of her, is an example of an individual with a life-long disability that constitutes a catastrophic situation. Ongoing health and disability related expenses steadily deplete personal and family financial resources.

People with disabilities are often unemployed, under-employed, and uninsured. Many are denied access to private insurance because they are considered high-risks. Government health coverage, under Medicare or Medicaid for example, often requires massive depletion of financial resources for eligibility, or present gaps in coverage, or cost-sharing provisions which similarly drain away scarce financial resources through out-of-pocket expenditures. It is imperative, therefore, that people with disabilities be afforded protections from catastrophic costs associated with disability and illness under any plan recommended by the committee.

The health care needs of persons with disabilities are best met along the entire spectrum of health care services. Current health insurance programs, meaning private plans and public programs, such as those under Social Security, fail to accommodate the long-range health needs of people with disabilities. For example, many private and public health insurance programs exclude coverage for rehabilitation services, especially those provided outside of the hospital. If coverage

for catastrophic illness is to be truly appropriate and cost-effective, it must include a broad range of health care and related services in alternative and community-based settings.

National data is not available to adequately assess the health care needs and patterns of health service utilization of people with disabilities. Indicators which reflect specific disabilities must be incorporated into current data collection and analysis efforts to ensure that the health care needs of persons with disabilities are appropriately and adequately addressed under catastrophic illness coverage policies.

It appears that much of the current debate on catastrophic illness focuses on elderly persons and their long-term care needs. Although this emphasis is understandable and very important, it underscores the need for education as to the disability and the ensuing need for access to comprehensive health and related services. In the past, some persons considered "Handicapped" or "Disabled" to include only the blind, deaf, or wheelchair user. The categories for the disabled have been expanded to include persons with diabetes, arthritis, heart conditions, and cancer.

Many disabled persons, and persons with either a prior or current history of a variety of medical conditions, cannot get health insurance at any price. Others have had their premiums raised until they are paying over \$800 per month or more for basic health insurance coverage. Still others can only purchase health insurance if they waive coverage for the very condition which disqualifies them and for which they are most likely to incur substantial medical costs.

It is imperative that people with disabilities not only have access to basic health insurance coverage, but to catastrophic health insurance as well.

We are aware that the committee is concerned with how such coverage will be financed. There are a variety of proposals being considered as solutions to the long-term-care problem. All of them have both positive and negative aspects. I would encourage Congress to continue to take steps to develop a comprehensive range of policy choices such as: restructuring the Medicare program; tax incentives for employers who offer catastrophic and long-term-care health insurance with premiums shared with employees; the concept of a medical IRA, and other feasible plans.

Whatever the final plan may be, we urge the committee to recognize and cover the rehabilitation and long-term-care needs of persons with disabilities.



PARALYZED VETERANS
OF AMERICA
Chartered by the Congress
of the United States

STATEMENT OF
JOHN H. MATHER, M.D.
ASSOCIATE EXECUTIVE DIRECTOR
FOR
MEDICAL AND RESEARCH AFFAIRS
PARALYZED VETERANS OF AMERICA
BEFORE THE
PRIVATE/PUBLIC SECTOR ADVISORY COMMITTEE
ON
CATASTROPHIC ILLNESS
AUGUST 12, 1986

I thank you for the opportunity to present the views and opinions of the Paralyzed Veterans of America (PVA) concerning the costs to society and individuals of catastrophic illness. I am pleased to be able to represent the interest of our membership as we are developing a greater understanding of extended longevity for all veterans. While the relevance of your deliberations to victims of spinal cord injury may be self-evident, they are also of concern to the rapidly aging veteran population in general and we trust that you will solicit testimony from the Veterans Administration (VA). The importance of input from the VA will be made clear in these remarks, especially as the evidence mounts that many veterans eligible for medical care in the Veterans Administration's health care delivery system will find it unavailable and inaccessible.

The Paralyzed Veterans of America, a national veterans' service organization chartered by Congress, has for four decades served the needs of its 12,000 members -- all of whom have incurred a spinal cord injury or dysfunction. Most of our membership have catastrophic paralysis, but virtually all of our members are handicapped as defined by Section 504 of the Rehabilitation Act of 1973, as amended.

Due to the nature of spinal cord injury and the prevalence of extensive medical and psychological complications associated with long-term disability, our membership is vitally concerned with the provision of quality health care.

Our veteran membership is composed of 50% World War II era veterans, 16 2/3% Korean Conflict and 33 1/3% Vietnam era, with the remainder having served in

peacetime. Even more so than traditional veterans' service organizations, PVA monitors the VA health care delivery system and any additional federal programs which may provide health care coverage to our membership.

Nationally, veterans are aging so that the aging phenomenon and its impact on long-term care is of great interest to PVA. The further implications of aging with a disability render today's hearing particularly appropriate to our organization.

During the past two years, our membership has become aware of its own extended longevity and the costs of chronic illness. Various studies have been initiated by PVA. Some are in the initial phase and others will be completed this fall. PVA asks that the record of the Advisory Committee remain open through this calendar year so that those documents unavailable today will be received, examined and inserted into the record.

The size and demands of the Nation's aging phenomenon are not easily grasped, but the implications, as extensively detailed in the medical and socioeconomic literature, are certainly arresting. Ramifications of what has been termed the "longevity revolution" are so broad and complex that this issue may well become the most compelling imperative driving the socioeconomic, political and ethical aspects of tomorrow's health care industry.

Although this is not the place for an extensive recital of demographic data, a quick reference to gross figures is perhaps in order.

Today, 30 million Americans are over the age of 65 with 2.6 million 85 or older. By the year 2000, there are expected to be 35 million over the age 65 and 12 million of those in the over 85 category. To maintain current levels of care, the elderly will, by the year 2000, require a 68% increase in nursing home beds and a 25% increase in hospital beds. In more dramatic terms, it calls for the opening of a 200 bed nursing home every day for the next fifteen years.

For one large group in the American population - America's veterans - the aging phenomenon or "geriatric imperative," and the changing needs which accompany it, are not a matter for future speculation. The VA is dealing with a beneficiary population whose average age is increasing at a rate far exceeding that of the general population. In 1980, the proportion of veterans 65 and over was approximately equal to that in the general population. By 1990, the proportion will be double the general population rate, and by 2000, that rate will nearly triple.

About a year ago, PVA commissioned, through its Spinal Cord Research Foundation, an inquiry into what is known and what is not known about aging with a physical disability. Dr. Roberta Trieschmann, a research psychologist, is currently completing the final revisions to the text of what will soon be released as a book entitled Aging With A Disability. Early in her research it became exceedingly clear that the concept of aging is closely tied to how we treat aging people in the United States, especially the type of health care services that we provide and do not provide to ease their burdens.

Prior to World War II, individuals with physical disabilities were not very visible in American society; a majority did not survive the acute injury or illness and those who did were not usually found in the mainstream of American life. However, the development of sulfonamides and antibiotics in the 1930's and 1940's changed the survival statistics so that by the end of World War II, we had a sizeable and visible population of persons with major physical disabilities incurred during active military duty. The polio epidemics of the 1940's and 1950's added a sizeable civilian population of persons with disabilities and now these groups are aging -- aging with a physical disability.

The population of spinal cord injured has always had large expenses associated with the acute injury and the continuing need for some form of sustaining long-term care. What is now of even greater importance is that the majority of public and private decisions about financing are oriented to the acute illness and injury while long-term disability is often defined as 18 months to 5 years after onset. As a result, it is evident that those with disabilities of 20 or more years are indeed a forgotten population.

There is much talk about a health care system in the United States, but actually we appear to be evolving more and more into an illness or sickness system. Because aging is not strictly a medical problem and because aging is not always necessarily a sickness which can be treated, a sickness treatment system, designed to attend mostly to biological-organic dysfunctions, is the worst of all possible approaches to the complex biopsychosocial environmental problem of aging. Rather, a more complete and balanced approach that recognizes the full spectrum of long-term care need is the strategy most

suited to meet the challenge. All of us are aging, all of us experience a decline in energy and altered physical function over time. For some, however, this very natural process is superimposed upon other impairments which have imposed a physical and financial penalty on daily life. Unfortunately for these people with major physical disabilities, the process of aging seems to increase the amount of the penalty.

In addition to an examination of the demographics and epidemiology of disease and disability, PVA has just completed the first phase of a year-long inquiry into the economic consequences of severe disability. While the former study by Dr. Trieschmann seeks to define the scope of issues, this study attempts to define the parameters of the "burden" of disability. Under the direction of Dr. Monroe Berkowitz, an economist, Rutgers University Bureau of Economic Research has recently provided us a report entitled Economic Consequences of Severe Disability.

Based on previous work limited to a spinal cord injured population in 1985, investigators expanded their work to include other disabled groups. A copy of the report will be made available to the Advisory Committee and will provide detailed information on the study's methodology. In general, the analysis demonstrates that the economic impact of differing disabling conditions varies significantly. Two econometric models are used in the study and an alternative to the prevalence-based, single-year estimate of the costs of spinal cord injury is developed. By organizing data from a variety of sources, the investigators prepared an estimate of the present value of expected future costs that would be incurred by someone suffering a spinal cord injury in 1986. This estimate in effect tells us what society would

gain through the prevention of a spinal cord injury. One can use the results of such analyses to evaluate the relative economic efficiency of efforts to prevent different disabling conditions. Parenthetically, the estimates of the lifetime costs of disability could be used to structure a fair compensation award for someone who has suffered a spinal cord injury.

Finally, the investigators incorporated data from two alternative data sources, the Survey of Income and Program Participation and the National Medical Care Utilization and Expenditure Survey. Using the surveys they developed an extensive collection of data on the socioeconomic and demographic characteristics of individuals who are indicated as disabled. Because the two surveys were conducted three years apart, the investigators were also able to study changes in the size and characteristics of the disabled population between 1980 and 1983. They observed an increase in the number of younger veterans who report being disabled, a higher percentage of nonwhites reporting a disability, and a clear increase in the disabled population as a whole. Such increases can be explained in different ways. One possibility is that disabling health conditions were in fact becoming more prevalent in these years, and another that worsening economic conditions in the early 1980's may have had a disproportionate impact on less advantaged individuals.

The issues of individual health status and personal economic wherewithal become intertwined when one becomes the victim of a catastrophic illness. Prolonged disability does have its economic consequences. Nonetheless, a problem which merits further study is establishing the extent to which the growing number of disabled people actually reflects changes in the prevalence

of their health conditions and the extent to which it reflects changes in labor market opportunities for the less advantaged. This problem and others will be included in Phase Two studies.

A final comment should be made in regard to some of the age effects noted in this study. There has been much discussion about the problem of aging, early retirement and disability. The impact of disability on individuals nearing retirement deserves attention, and possibly corrective action. At the same time we should not overlook the potential effect economic conditions may be having on younger persons with health problems. If the disincentives to seek rehabilitation become especially strong after one begins receiving disability benefits, then an extra effort should be made to avoid this outcome. If onset of disability at younger ages is a consequence of economic decline, we face the prospect of increasing numbers of people being drawn into a long-term disabled population which is difficult and costly to rehabilitate.

The VA has been aware for some time of a very special opportunity and challenge it has as a result of the aging of its client population. Over the past decade, VA researchers and clinicians have been at the forefront in the developing field of gerontology and geriatrics -- the study of aging and the care of the aging members of a population, respectively. For a number of years the term "geriatric imperative" has had common usage in the VA. The VA issued a report entitled The Aging Veteran in October of 1977, and the VA has worked for the past decade to develop programs in geriatric research, education, and clinical care, including pilot programs to deal with the aging population. The VA has conducted and supported studies and surveys to assemble information to try to get a real fix on what the challenge of the

future will be. In 1984 the VA published a report entitled Caring for the Older Veteran. The result of more than two years of study, advisory input, contract consultation and review, the plan provided an overview, based upon demographic projected need, of the opportunities presented by the aging of its constituents. Because the VA is dealing with a population whose average age is increasing much faster than that of the population in general, it was hoped that a VA accommodation to this impact would serve as a proving ground for national programs to follow. The VA has the advantage of starting with an on-line comprehensive coordinated system which includes both the medical and social components considered essential to an effective geriatric effort. All the key elements of a basic structure to meet the spectrum of needs of the older veteran are either in place or they exist in pilot form.

In developing this report, a fundamental issue for the VA was to project the real need for future care for which the VA might be responsible. Since the VA had no reliable information on future changes in Medicare and Medicaid, it made projections based on the assumption that Medicare and Medicaid would continue to meet the same needs as previously met. This meant that of all veterans 55 and over in the country, some 37% of them had Medicare coverage. Of those 65 and over, about 90% were covered by Medicare -- both Parts A and B in most cases.

It is clear from the VA's report that the VA's health care system in and of itself cannot achieve sufficient growth and resource capability to meet adequately the needs of its veteran constituency. The VA's Department of Medicine and Surgery is able to provide a comprehensive array of health care services to eligible veterans, ranging from acute medical care to adult day health care. However, the Department is not authorized to provide a broad

spectrum of health related or social welfare services. For example, the Department does not provide, directly or through contract, home chore services, meal preparation, or shopping services.

Other avenues do make it possible for veterans to obtain these health related/social support services. First, certain veterans who receive service-connected compensation or the nonservice-connected pension benefits from the VA are eligible for additional income support based on conditions rendering them "permanently housebound" or in need of aid and attendance. These higher rates reflect an individual's disabilities, which require additional assistance in daily activities, and assist the individual veteran in purchasing needed and desired services. The second source of assistance for the older veteran in need of supportive services is the veteran's own community. The array of community-based programs, funded through Federal, state, local, and private agencies, is available to the frail elderly veteran as a citizen, although comprehensive community services are not universal.

While the VA operates within the context of its statutory authority, the Agency needs to reexamine its role and future development of community-based health care and health related services. This remains a critical area of exploration, especially as these community services affect the quality of life and independence of the elderly and severely disabled and the efficient and effective utilization of institutional health care. The Agency's report, Caring for the Older Veteran, and Harvard University's report Older Veterans: Linking VA and Community Resources contain numerous ideas and recommendations

on future approaches to community based care and its systematic development and coordination.

It is this notion that the VA and its health care delivery system cannot operate in isolation, apart from the rest of the Nation's health care programs, which is the subject of a third study sponsored by the Paralyzed Veterans of America. The possibility of continued horizontal leveling of the VA's health care system through arbitrary budget decrements will render it incapable of handling its share of the "geriatric imperative." The Congress enacted a new "means test" for non-service connected veterans this year but this does not address what the VA share is or how it can best be provided. These decisions will need to be made in the context of a comprehensive review and a strategic reform process applied to all of the interrelated federal health care programs addressing the needs of the disabled and those who are aging.

In mid-1985, we contracted with the American Health Planning Association to undertake a study of the impact of selected policy changes affecting veterans' health care benefits. PVA wanted to know the effects of various proposed changes on veterans at the community level, where care is rendered. There was a particular interest in the interactions among VA care and care rendered in other sectors, and among VA's several missions.

Among the concerns expressed at the outset were:

1. Whether selected policy changes would result in veterans who were

receiving care currently losing access, and, if so, what the potential for them to find equivalent care in their communities might be.

2. Whether the growing needs of older veterans could be met effectively by the VA under its current plans for development of geriatric and long-term care services.
3. Whether policies which depended on collection from veterans' health insurance carriers could be expected to make a real difference in the financing picture for VA care.
4. Whether severe budget cuts which might make it necessary to close entire VA facilities could be accommodated, while retaining services to those veterans who currently use the system.
5. Whether closures made to meet budgetary goals would have adverse effects on VA's non-patient care missions -- medical education, medical research, and backup to the Department of Defense in times of national emergency.
6. Whether closures made to achieve federal budgetary goals would shift substantial costs from the federal to state and local health care budgets.

The study is moving into the final phase of analysis and completion of its findings with appropriate recommendations. The current plan for its release is in early October of this year when the final series of recommendations

will be available. However, there is one issue which has emerged as the dominant theme. This is the unifying theme of interactions. It is impossible to consider any one mission of the VA's medical care component in isolation from the others. It is equally impossible to consider the VA and its medical services without looking at the larger health care system in the country. Considering these things in isolation, of course, would simplify analysis. It allows generalizations concerning the effect, or lack of effect, of changes in one component of a system, or one system within a larger system. Analysis in isolation, however, produces results which may not hold up in the dynamic real world of systems interactions.

The interaction issue is a major concern underlying PVA's interest in this study. The non-system approach to budget development, review, and enactment at the federal level can lead to decisions in regard to one agency or program without consideration of the decisions' impact on others. This problem is pervasive in the consideration of health issues, where various elements of the total federal health responsibility lie in different budgetary units, and fall under the jurisdiction of different Congressional committees. This problem becomes particularly acute in times of financial stringency, when efforts to contain expenditures in one program may lead to unanticipated consequences in another, and when "acceptable" cuts in two programs may have a synergistic effect, causing problems greater than the sum of the individual cuts.

These interactions exist everywhere, but two examples are worthy of note:

1. The interactions between VA policies and those governing Medicare are increasingly important as the veteran population moves rapidly into the Medicare age group. About 90 percent of the veterans over 65 are Medicare eligible. If costs to the individual Medicare recipient continue to rise, the alternative of VA care may become more attractive to those who meet the eligibility criteria but who do not now use VA services. On the other hand, the opportunity for Medicare beneficiaries to enroll in HMOs offering a wide range of services at a minimum out-of-pocket cost (at least when compared to traditional Medicare coverage) may attract Medicare eligibles who now use VA services.

2. The interaction problems are even more difficult to deal with once the federal arena is left behind and the focus moves to the state and local levels. Current veteran users of VA care are often without means of financial access to private health care, and their costs are shifted to the state Medicaid and indigent care programs, or to local charity institutions.

Many conclusions and recommendations from this study are currently under review but two general statements can be made.

1. Policies affecting the amount and scope of acute care services provided veterans under VA auspices cannot be established in isolation from those affecting other parts of the health care system, particularly those which govern public programs for the medically indigent and the elderly.

2. The nation's community nursing home bed capacity is limited, and VA would end up competing with non-VA patients for available community beds, a fact which would have adverse cost effects both for VA and for other payers for nursing home care services.

As soon as this study is released, the Committee will receive a copy.

Congressman Waxman has rightly stated that, "If we rely solely on competition in the health care market place, millions will be denied access to needed care, for no one competes for the poor, the unemployed or the chronically disabled." The highest incidence of that deprivation is likely to be visited on the swollen ranks of the elderly and the chronically disabled.

Your Committee is to be commended for its effort to consider in some depth the underlying policy issues inherent in the need to ameliorate the costs of catastrophic illness and hopefully to influence the focal point of Congress in further health care legislation. It would seem thus far that the federal government, in its effort to reduce health care costs, has invested almost exclusive faith in the efficiency of market principles and is placing full responsibility on the providers of care to render treatment within the financial limits set or eventually go broke. Continued pursuit of this technique can only force additional inequitable cost shifts, risk the compromise of the quality of medical care and assure the denial of care to many of those for whom there is no financial compensation.

The review by the Advisory Committee is made all the more necessary since the change in the composition of the elderly and disabled population comes at a time when Congress should consider not just spending reductions, but the very nature and the structure of all the funding streams for health care, including Medicare.

Medicare is essentially a health insurance plan for acute illness. Very few of its resources finance chronic care and little coverage is provided for out-of-institution services. Medicaid provisions should be modified for more appropriate and equitable resource allocations. Programs are needed that would encourage a proportionate consumer sharing of financial costs for long-term care. The "all or nothing" rule of eligibility, requiring "spend down" to poverty level for welfare aid needs serious rethinking. This same "spend down" principle is a component part of the recently enacted "means test" for non-service connected veterans. There are several important aspects to a systematic reconsideration of all programs such as Medicare, Medicaid, Social Security and the various sponsored social services. Added to these I would certainly include VA medical, health and socio-economic programs.

The case for strategic reform is well made in an excellent article appearing in Health Affairs by Dorothy Rice, the previous director of the National Center for Health Statistics and Carroll Estes, consultant to the U.S. Senate Committee on Aging. Their guidance consists of four basic principles for measuring the effectiveness of long-term care policies:

"First, it must be comprehensive, including a full range of health and social services covering the long-term care continuum from community-based care to institutional care. It must also include preventive and restorative services as well as treatment and illness management. Long-term care services must be linked with other health and social services as with hospital and physician services. Second, it must provide incentives for providers to keep costs at a reasonable level, to prevent overutilization and to promote the use of appropriate services. Third, it must have a financial system that provides protection from impoverishment to individuals who need long-term care, and that allows for combining private and public resources to assure protection for individuals before they become ill. Fourth, it must ensure access to those who need the services regardless of financial ability to pay and regardless of age or type of disability."

America's health care delivery systems are in great turmoil. Multiple vested interests and agents are studying health system restructuring and revenue reform. Long-term care policies are under review in the Brookings Institute, the National Institute of Medicine, the AMA and the AARP, among others. Unless your committee deals with the plights of the elderly and disabled and addresses the policy issues critical to their needs, their future will be shaped by the unfortunate policy of "benign neglect".

We are given to understand that this Committee is considering a variety of options for protecting individuals from the financially ruinous costs of a catastrophic illness, whether of an acute or continuing nature. Such proposals include:

- o Requiring all employers to include catastrophic provisions in worker health insurance;
- o Expanding Medicare and Medicaid;
- o Providing government subsidies for non-federal catastrophic policies;
- o Giving tax breaks to encourage individuals to buy private-sector "add-on" catastrophic policies;
- o Authorizing "medical individual retirement accounts"; and
- o Making it easier to convert home equity to cash for nursing-home costs.

We understand that about half the population has some form of catastrophic insurance. When the costs of care do exceed this coverage, the impact can be devastating. Of the more than 30 million under 65 who have no health insurance, the effects are more than devastating. For the spinal cord injured, these and many other permutations apply.

It is appropriate here for PVA to indicate that we are not wedded to any one particular proposal because we believe the solution does not reside in one simple approach or tinkering with existing mechanisms. Whatever comprehensive proposal is forthcoming should be consistent with the recognition that a catastrophic acute illness is often followed by a period of long-term care that can be as catastrophic, if not more so. The following general principles would seem to be most relevant to devising a suitable financing mechanism for a catastrophic illness:

1. Cover all ages;
2. Provide universal coverage irrespective of physical disability or mental impairment;

3. Emphasize incentives for maintaining an individual's functional independence;
4. Provide for pooling of risk through financing derived from various defined sources;
5. Reduce the dependence on government funding except to assure universal coverage;
6. Provide a coherent system of financing that avoids significant cost shifts and cost transfers;
7. Ensure continuation of and reliance on the informal support system; and
8. Ensure that attention to costs and efficiency do not adversely affect quality and effectiveness.

In conclusion, the Paralyzed Veterans of America is vitally interested in the work of this Committee and looks forward to providing additional input in the near future from the reports we have in process. There is information and resources at our disposal which we can mobilize to attempt to answer questions before you. I will be pleased to follow-up on any such requests and I look forward to the opportunity for a continuing dialogue.

Respectfully submitted.

Consortium for Citizens with Developmental Disabilities

January 21, 1987

Honorable Edward Kennedy
U.S. Senate
113 Senate Russell Office Building
Washington, D.C. 20510

Dear Senator Kennedy:

The Health Task Force of the Consortium for Citizens with Developmental Disabilities applauds your early and aggressive efforts to articulate a national health policy agenda for the 100th Congressional session. As a 50 member coalition of national organizations representing the more than six million of our country's citizens with developmental disabilities, CCDD has a particularly heightened concern about the difficulties faced by the many uninsured and under-insured Americans.

Statistics about the individuals we represent indicate that most of them would be counted among the overall uninsured and under-insured population. People with disabilities are three times more likely to be in poverty; they are significantly represented among the chronically unemployed with 62% of people with handicaps aged 16 to 64 not in the labor force; and most fall through many of the presumed health care safety nets structured at the state and federal levels.

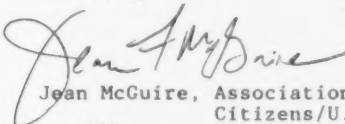
For those with developmental disabilities who may have access to private coverage through family members, pre-existing condition exclusion clauses pose barriers to effective care. Those relatively few individuals who finally access private coverage often find that their disability-related health care needs are inadequately covered. Usually this is a reflection of the serious limitations in the benefit packages available in the lower paying service sector jobs people with handicaps are likely to hold. For these reasons, the people we represent face, in an exacerbated way, the access, affordability, and coverage concerns articulated so well by the many witnesses you heard from last week...and yet, among those witnesses were no representatives of the disability community, and essentially no remarks directed to our particular concerns.

Many of our organizations have, for some time, supported the development of a national health insurance/health care mandate. However, we are very concerned about the fact that much of the discussion of this goal does not adequately incorporate, and in fact has often pointedly excluded, the concerns of people with disabilities. A notable example of that is the exclusionary method of data collection used for most of the federal health care utilization indices (which usually omit people in institutions and others with disabilities) which are being used as the basis for many of the current health care coverage proposals.

Your history of concern and action on behalf of individuals with developmental disabilities assures us that the needs of the people we represent will not be lost as you move forward with your various proposals. We are pleased that the record was left open and have therefore included in this package for your committee's review the various statements provided to the HHS Catastrophic Advisory Committee by member organizations of CCDD. Our Health Task Force, as well as the rest of the CCDD membership, will be available to further discuss these issues with your staff.

Thank you in advance for your continuing investment in the future of our nation's citizens with disabilities.

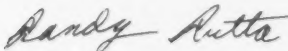
Sincerely,



Jean McGuire, Association for Retarded
Citizens/U.S.



Richard Nugent, Epilepsy Foundation of America



Randy Rutta, Easter Seals Society

Co-chairs, Health Task Force,
Consortium for Citizens with Developmental Disabilities

Consortium for Citizens with Developmental Disabilities

STATEMENT RESPECTFULLY SUBMITTED

TO THE

PRIVATE/PUBLIC SECTOR ADVISORY COMMITTEE

ON CATASTROPHIC ILLNESS (DHHŠ)

BY

DIANA J. PILLAS

ON BEHALF OF THE

CONSORTIUM FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES

AUGUST 12, 1986

Member organizations of the
 Consortium for Citizens with Developmental Disabilities
 submitting this testimony:

American Association on Mental Deficiency
 American Physical Therapy Association
 Association for Retarded Citizens/U.S.
 Association for the Education of Rehabilitation Facility Personnel
 Conference of Educational Administrators Serving the Deaf
 Convention of the American Institute for the Deaf
 Council of Organizational Representatives
 Epilepsy Foundation of America
 International Association of Psycho-Social Rehabilitation Services
 National Alliance for the Mentally Ill
 National Association of Developmental Disabilities Councils
 National Association of Private Residential Facilities
 for the Mentally Retarded
 National Association of Protection and Advocacy Systems
 National Association of State Mental Retardation Program Directors
 National Head Injury Foundation
 National Rehabilitation Association
 National Society for Children and Adults with Autism
 The Association for Persons with Severe Handicaps
 United Cerebral Palsy Associations, Inc.

For Further Information Contact:

Jean McGuire (785-3388)
 Association for Retarded Citizens

OR

Richard Nugent (459-3700)
 Epilepsy Foundation of America

Members of the Committee:

Good morning. My name is Diana Pillas, and I am here today representing not only the Consortium for Citizens with Developmental Disabilities (CCDD), a coalition of over 50 national consumer, professional and provider organizations, but more importantly the millions of Americans represented by these organizations - people with developmental and other disabling conditions such as autism, cerebral palsy, communicative disorders, epilepsy, head injury, hearing impairments, learning disorders, mental illness, mental retardation, spina bifida and vision impairments.

As a past chair of the Developmental Disabilities Council of the State of Maryland, I have had extensive experience working with children and adults who have a developmental disability as well as organizations concerned with the specific problems experienced by people with developmental disabilities. As a member of the board of the Epilepsy Foundation of America and as part of the clinical care team of the Epilepsy Center at Johns Hopkins Hospital, I am reminded daily of the health care needs of people who have serious health or disabling conditions as well as the financial restraints imposed upon health care providers.

Utilization statistics partially portray the catastrophe presented by the frequency of care required by individuals with disabilities. The 1984 edition of the Digest of Data on Persons with Disabilities highlights the results of those disability-related components of the National Center for Health Statistics 1979 Health Interview Survey. Although the data base is now old and its disability descriptors are limited, a clear picture of heightened

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physician visits and hospital utilization is set forth. People with chronic activity limitations reported physician visits at twice the average length reported by the rest of the population. Short stay hospital visits ranged up to three times as frequent while length of stay as much as doubled.

We are very pleased with Secretary Bowen's aggressiveness in undertaking the President's mandate regarding catastrophic health care needs, and are here today to request that the Committee assure that its forthcoming policy recommendations thoroughly address the health care needs of Americans with disabilities.

These individuals include a broad cross-section of the poor and not so poor, the young, and not so young, the healthy and the seriously ill. Many of these individuals are clearly not receiving the same level of care as the overall population.

We are concerned, however, that the needs of these individuals may not be adequately addressed in your final report given our review of several documents drafted for the Committee's deliberations.

Rejected by health insurance companies or protected by standard plans which do not cover on-going maintenance needs, many persons with disabilities face catastrophic medical expenses for (1) acute care for those under 65, (2) acute care for those over 65, and (3) Long Term Care for all age groups. They frequently experience health care expenses of a catastrophic dimension because of the indeterminate and usually lifelong duration of their disabilities;

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because of the diverse and changing health care needs they face; and because many people with disabilities have extremely limited income.

Health care becomes a catastrophic expense when out-of pocket health expenditures exceed a certain level of income. "Catastrophic" refers to the impact on an individual's income and not to the type of care or the setting in which it is provided. The subject of catastrophic health care involves not only a concern about insurance coverage, but also about the absence of any insurance for in-home care. Like other people, most people with disabilities want to meet their health needs living in the community in their own homes -- not in medical institutions like hospitals or nursing homes. One of the important goals of a meaningful catastrophic health care plan is to develop a reimbursement mechanism for community-based and in-home care which will reduce the need for institutional care. This is a pressing need which must be acknowledged by the Advisory Committee.

It must be pointed out that many individuals with a disability do not have health care needs which differ significantly from the overall population. Nevertheless, they are more likely to incur medical expenses of a catastrophic nature given their income. Severely limited access to appropriate health care and related services in the private sector has devastated the lives of many individuals with disabilities and their families. All too frequently they have been forced to bankrupt themselves in meeting ongoing health care costs. Otherwise unnecessary institutionalization has occurred.

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Inaccessibility to health insurance:
The single greatest disincentive to work

What is also universally experienced by individuals with disabilities is unwarranted and unfounded discrimination in gaining access to health insurance coverage. Adequate health insurance coverage is either unaffordable or unavailable at any price. Insurance companies erroneously view all individuals with a given disability as a higher risk. The insurance industry fails to assess each individual based on his or her specific condition. This more appropriate approach, mandated for recipients of federal financial assistance by Section 504 of the Rehabilitation Act of 1973, is increasing reflective within society as a whole.

Louis Harris and Associates, earlier this year, released the findings of the first comprehensive survey of the attitudes and beliefs of people with disabilities or severe health conditions. This survey, based on 1,000 interviews, found that 18 percent or an estimated 2.3 million of the individuals with disabilities or severe health problems who are aged 16 through 64 were not covered by either private or government health insurance.

To this number of working age individuals must be added an unknown number of children with serious health conditions or disabilities whose parents are unable to provide either insurance coverage or whose policies preclude expenditures stemming from the child's pre-existing condition.

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Risk Pools: A Partial Solution

The customary and continuing failure to address Long Term Care needs under catastrophic insurance proposals is hardly mitigated by a reliance on high risk health insurance pools. Risk pools are designed to provide a mechanism for purchasing health insurance by persons rejected by insurance companies for pre-existing conditions. The central concept of a high risk pool is to distribute health care costs between people with pre-existing conditions and all policyholders through an assessment on health insurance companies, health maintenance organizations or employers in proportion to the amount of business they do in a specific state. Despite this useful design there are significant problems with risk pools.

First, they are not affordable to most persons with disabilities or chronic health conditions. And secondly, their "comprehensive" benefits do not cover many of the on-going maintenance needs which persons with disabilities have. They could become a better vehicle of insurance if they were created with a public subsidy on a sliding scale of the premiums and deductibles of high risk pool participants. States may be more willing to subsidize the high premiums and deductibles if they had the option of using Medicaid dollars for all persons who are rejected by private insurance companies because of pre-existing conditions.

It would also be more useful if the benefits under risk pool plans covered all disability-related expenses identified as medically necessary by a physician, including: (1) prescription drugs and other medications,

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(2) durable medical equipment for purchase and repair, (3) disposable medical supplies necessitated by bodily functions, (4) maintenance occupational or physical therapy and (5) medical rehabilitation. These items and services should be covered under home care as they would be covered if the insured was hospitalized.

The availability of these health care services can enable persons with a disability to live more independently and productively in community based settings at substantially less cost than in institutional care settings which our current service system is biased.

We would also recommend the Advisory Committee examine the following:

1. an extension of Medicaid eligibility for SSI recipients who need Medicaid in order to work through permanent authorization (Section 1619 of the Social Security Act) with automatic re-entitlement to SSI benefits when earned income drops below the break-even point (this will also require the elimination of the 209(b) option in fourteen states which do not automatically provide Medicaid eligibility to SSI recipients);
2. a Medicaid buy-in plan with sliding scale premiums for disabled persons who are not eligible for Medicaid when they work;
3. a Medicare buy-in plan with sliding scale premium for Part A and broadened Part B benefits for SSDI recipients who choose to work;

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4. Private wrap-around coverage with publicly subsidized premiums to supplement standard health insurance policies which are inadequate for disability-related expenses;

5. Private insurance mandates for disability-related expenses in recognition of the fact that all policyholders are at risk of becoming disabled and that non-disabled persons are really only temporarily able-bodied. In addition, it is imperative that standards be developed at the federal or state levels to close discrimination loopholes in eligibility and pricing of insurance policies.

6. HMO coverage for persons with disabilities should not jeopardize access to specialists outside of the HMO, and steps should be taken to assure that HMOs do not postpone higher cost preventive or intervention services that are essential to a disabled person's long term care needs.

7. Persons who need personal care attendants should be eligible for a public subsidy on a sliding fee scale or through coverage extension within private plans.

8. The feasibility of an insured pool which combines persons with disabilities with low risk uninsured person should be carefully explored. Group policies presently encompass people with different needs. Little is it recognized that many people who would be

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considered "uninsurable" if they applied for individual health insurance are covered by group policies. Medical uninsurability has more to do with the size of the group with which one shares risk than with the nature of one's health status. Funding for an uninsured pool could come from a redirection of existing public subsidies to the uninsured, subsidized premiums on a sliding fee scale, a tax on insurance companies and other health care providers, and contributions from self-insured employers and from employers who could not afford the premiums in the absence of a public subsidy for low-wage workers.

9. Greater flexibility must be built into the Prospective Payment System to more accurately reflect the actual cost of providing acute health care services to people with severe disabilities and health conditions.

These priorities for persons with disabilities should be carefully considered in developing a meaningful approach to catastrophic insurance.

An Expanded Data Base Is Critical

To effectively incorporate people with disabilities into the health care policy planning process, it will be necessary to accurately reflect their service utilization needs. Although the 1984 survey presents more disability related items than most of our national bases and gives a helpful gross

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picture of utilization. it does not begin to adequately profile the health care needs of people with disabling conditions for two major reasons:

o first, it does not reflect the diversity of the disability community (among other deficiencies it does not incorporate the institutionalized population), and

o secondly, it does not delineate the breadth of health services intrinsic to their needs.

As we have embarked upon presenting a health care agenda for people with disabilities, we have repeatedly found a lack of adequately detailed data upon which to credibly base assumptions our anecdotal experience dictates.

People with disabilities have simply not figured into the health care planning process. Our strongest recommendation to the Committee is that there is a critical need to restructure health care data bases to accurately describe people with disabilities and their health service needs.

Assuring that individuals with disabling conditions are adequately portrayed in the health care schema does more than simply provide a better basis for service provision and coverage for these individuals. It will structure a sufficiently broad schema for health care planners to anticipate the needs of the rest of the population who may "age into" disability or illness.

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The disability community has been on the forefront of establishing the efficacy and cost efficiency of home and community based social and rehabilitative services in its deinstitutionalization efforts. It is time for the health service arena to move more aggressively in this direction to address not only cost containment, but more importantly, to preserve the family unit and to bolster the ability of individuals to maintain themselves as independently as possible within their own community. We would earnestly support coverage as expansive as possible for community and home based service provision.

We realize the impediments facing effective transfer of the service focus to the community, but are assured of the importance of doing so in the process of redefining and redesigning both short and long term care options.

The CCDD appreciates this opportunity to appear before the Advisory Committee. We offer whatever assistance we can provide to you and your staff to ensure that your final recommendations meaningfully address solutions to the health care needs of people with disabilities or chronic health conditions.



TESTIMONY
PRESENTED BEFORE
THE
PRIVATE/PUBLIC SECTOR ADVISORY COMMITTEE ON CATASTROPHIC ILLNESS
ON BEHALF OF
THE ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES
AUGUST 12, 1986
WASHINGTON, DC

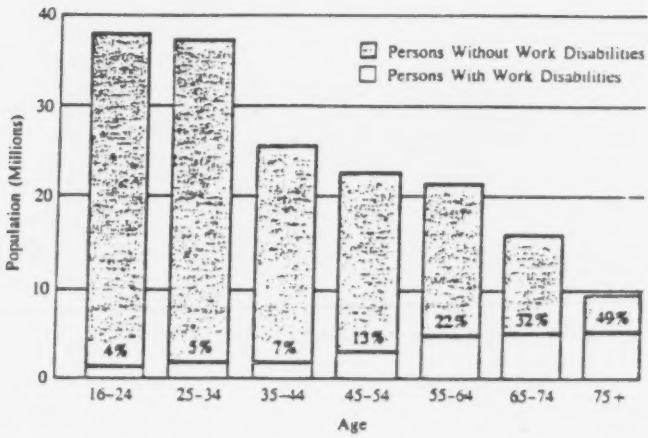
Submitted by:
Elizabeth Boggs, Ph.D.

Members of the Advisory Committee... I am Elizabeth Boggs, a founder and past president of the Association for Retarded Citizens of the United States, a current member of our national Governmental Affairs and Insurance Committees, and a parent of a forty-one year old son with severe mental retardation and other physical disabilities. I am here today on behalf of the ARC and the more than four million Americans with retardation represented by our membership. The experience of many within our organization in attempting to address the catastrophic consequences of disability has been one of frustration, sometimes intimidation, and, most often, one of limited success. We are, therefore, pleased to have this opportunity to address the significant and ongoing catastrophic care concerns of people with retardation, and to add our support to those issues being presented by the broader disability community.

The Association for Retarded Citizens of the United States commends Secretary Bowen and the Committee for recognizing that severe chronic disability is intrinsically catastrophic. Whether it be five years of terminal cancer, ten years of dying with Alzheimer's disease or ALS, forty years living with paralysis resulting from a youthful spinal cord injury, or a life time living with hemophilia, phenylketonuria, spina bifida, fragile X syndrome or any one of a myriad of birth defects, the negative effects are cumulative, not only for the person with the disorder but for immediate family members.

In this statement we wish to concentrate on those disabilities that arise early in life and more particularly on

Chart 1: Adult Population by Age in 1980



SOURCE: National Council on the Handicapped

mental retardation. Here "family" usually means parents (and later perhaps siblings) of the disabled individual, be he or she infant, child, adult or even aging adult. Despite the common image of the individual with retardation as a child, it is not uncommon to find a sixty year old retarded adult living with an eighty year old parent.

Disabilities are experienced differently at different ages. In addition, disabilities of early onset differ in many ways from those that are first manifest in middle and late life. As shown in Chart 1, taken from the 1986 report of the National Council on the Handicapped, prevalence of disability increases with age. What is less often appreciated is the relative gravity that has to be attached to the needs of people who are disabled in early life when one considers their prospective cumulative years of disability. The 4% disability rate among people 16-24 means 1.4 million versus 4.8 million people at a 22% rate among those between 55 and 64. Yet the former are likely to outweigh the latter in total man years of disability over the life span. It is to the truly catastrophic effect of this lifetime burden that we wish to call your attention.

THE EXTENT OF DISABILITIES OF EARLY ONSET

You have heard from other witnesses about the inadequacy of documentation, fiscal or demographic, that can differentiate among persons whose needs vary by age, degree of disability, nature of impairment, age at onset, prior work history, family availability,

and many other relevant factors. We share these concerns. They have been corroborated by Butler, Budetti, Mc Manus, Stenmark and Newacheck (1985), who described the children's field, as follows:

Because chronic disability is the high-cost sector of children's health care one might expect that the financing of services in this realm would have been carefully documented for policy purposes and would have received ample attention in the health services research literature. As it turns out, however, patterns of private and public expenditure on the health care of chronically ill children (how much is paid, who pays, and for what kinds of services) remain poorly documented and understood. In particular, no national data base exists that would permit an understanding of specific child illness and family background characteristics as these relate to amounts and sources of private and public payment, either at a single point in time or over the life of the child. Instead, there exists a fragmentary and complex assortment of partial data sources, including elements of national interview surveys, Crippled Children Services program reports, state Medicaid descriptions, hospital records, disease-oriented studies, and anecdotal materials. Such data enable only a partial analysis, even at the level of simple descriptive statistics.

If this is true for child health after 50 years of federal attention to handicapped children, it is not surprising that data on non-elderly adults with disabilities is also fragmentary. In recent years, despite the valiant efforts of the National Center for Health Statistics, things have not improved. Adding to the difficulties is the deplorable 1981 mandate of OMB that severely curtailed the data gathering activities of many agencies in the Departments of Education, Health and Human Services, and others. In particular the interruption of serial surveys has made it harder to identify trends in a timely manner.

Even for those federal activities that continue, there are problems of definition and standardization. Age at onset is a significant factor in the life history of a disabled person yet data is rarely gathered systematically on it. Many surveys of the

National Center for Health Statistics depend on self reporting, and therefore, we believe, tend to under-report conditions that are considered stigmatizing such as mental disorders. Because people who receive Social Security or SSI benefits based on disability have each had an individual professional assessment (diagnosis with evaluation of impairment), we found programmatic data published by the Social Security Administration (SSA) very useful, particularly now that coverage is so nearly universal.

Between 60 and 65% of all persons who qualify in a given year for social security disabled worker benefits (SSDI) are over 50 when the benefits are first awarded. The most common diagnoses in this age group are heart disease, emphysema and arthritis. About 70% of the 2.7 million current SSDI worker beneficiaries are between 50 and 65. Since all of them must have a prior history of employment sufficient to entitle them to social security coverage, relatively few have disabilities first manifest as severe in childhood. This is confirmed by the finding that less than 1% were identified for special education placement while of school age.

By contrast, the half million plus disabled beneficiaries who are entitled as "adult disabled children" (or "childhood disability beneficiaries" (CDB)) of covered deceased, retired, or disabled workers, by definition, became disabled before age 22 and have been continuously disabled since then. The most common diagnostic groups include mental retardation, (a primary or secondary diagnosis in about two thirds of all CDB cases), childhood mental illness, autism, cerebral palsy and epilepsy.

Other significant diagnoses include spina bifida, cystic fibrosis, blindness, and deafness. When severe, these are referred to collectively as developmental disabilities. The majority of these disabilities are apparent by age six and many are associated with impairment of intelligence or learning capacity.

The members of the CDB group are the tip of the iceberg of adults disabled in childhood because their identification as such is delayed until at least one working parent retires, dies or himself (herself) becomes disabled as a covered worker. The median age of those becoming entitled as adult disabled child beneficiaries on the retirement of the working parent is about 30, although by definition they have all been disabled much earlier. (Eligibility can start at age 18 if the covered parent is eligible for benefits at that time.)

Approximately one out of every hundred retiring workers brings a childhood beneficiary onto the rolls. It is reasonable to infer that there are over one million potential childhood disability beneficiaries among the disabled sons and daughters of current workers under age sixty who are insured for retirement. These are in addition to the half million currently receiving such benefits. (This estimate of potential adult child beneficiaries includes an undetermined number of minor children of younger insured workers. It is an underestimate of prevalence in that it does not take into account individuals now living with these characteristics but who will predecease their parents and hence not qualify for CBD.)

It should be borne in mind that the Social Security definition of disability is "functional", and based on the presence of a severe physical or mental impairment that has the effect of preventing an individual from engaging in "substantial gainful activity." The same definition is used for adults in SSDI, CDB, and for Supplemental Security Income (SSI). An "equivalent" severe functional impairment may also qualify a child for SSI based on disability. It has been estimated that 4 million children have "functional" disabilities that interfere with "normal" activity for age such as doing school work, playing games, or working around the house.

While this discussion has had as its primary focus delineating our current and yet still inadequate data bases for describing the disabled population, there is an additional point to be made relative to the increased utilization of functional descriptors of disability. Giving further indications of a trend toward describing the severity and the catastrophic components of disability relative to functional indicators is the following table which appeared in the 1984 Digest of Data on Persons with Disabilities and was prepared from data compiled by the National Center for Health Statistics. This data profiled the chronic health problems of the individuals surveyed relative to their need for the assistance of another individual in meeting daily life needs, thus characterizing disability-related needs based on an underlying medical condition in other than a traditional health context.

PERSONS USING SPECIAL AIDS FOR GETTING AROUND, BY AGE AND SEX: CIVILIAN NONINSTITUTIONALIZED POPULATION, 1977

Age and sex	Persons using 1 or more special aids			Cane or walking stick	Special shoes	Brace		Walker	Wheel chair	Crutches	Artificial limb		Other mobility aid
	Total	1 type only	2 or more types			Leg or foot	Other				Leg or foot	Arm or hand	
Thousands of persons using special aids	6,459	5,292	1,167	2,714	1,492	398	1,004	689	645	613	205	66	205
Sex													
Male	3,106	2,519	586	1,239	717	241	519	203	294	348	146	49	124
Female	3,353	2,773	581	1,475	760	157	465	486	351	265	60	16*	81
Age													
Under 15 years	732	651	81	0*	512	76	51	22*	47	50	13*	6*	21*
15-44 years	1,067	906	161	153	705	133	296	26*	116	211	46	11*	36
45-64 years	1,674	1,333	342	550	1,139	119	460	91	148	202	82	26*	79
65 years and over	2,985	2,401	584	2,011	2,513	70	196	549	314	151	64	22*	68
65-74 years	1,194	913	281	723	1,027	44	134	168	151	97	40	9*	32*
75 years and over	1,791	1,488	303	1,287	92	27*	62	381	183	54	24*	13*	37
Number using aids per 1,000 population	30.4	24.9	5.5	12.8	7.0	1.9	4.7	3.2	3.0	2.9	1.0	0.3	1.0
Sex													
Male	30.3	24.6	5.7	12.1	7.2	2.4	5.3	2.0	2.9	3.4	1.4	0.5	1.2
Female	30.5	25.3	5.3	13.4	6.9	1.4	4.2	4.4	3.2	2.4	0.5	0.1*	0.7
Age													
Under 15 years	14.2	12.6	1.6	0.0*	11.1	1.5	1.0	0.4*	0.9	1.0	0.3*	0.1*	0.4*
15-44 years	11.2	9.5	1.7	1.6	2.8	1.4	3.1	0.3*	1.2	2.2	0.5	0.1*	0.4
45-64 years	38.6	30.7	7.9	12.7	9.2	2.7	10.6	2.1	3.4	4.7	1.9	0.6*	1.8
65 years and over	134.1	107.8	26.2	90.3	11.4	3.1	8.8	24.7	15.0	6.8	2.9	1.0*	3.1
65-74 years	83.7	64.0	15.7	50.7	11.4	3.1	9.4	11.8	10.6	6.8	2.8	0.6*	2.2*
75 years and over	223.7	185.8	37.8	160.7	11.5	3.4*	7.7	47.6	22.9	6.7	3.0*	1.6*	4.6

*Figure has low statistical reliability or precision (relative standard error exceeds 30 percent)

SOURCE: National Center for Health Statistics, 1977 National Health Interview Survey, data reported in *Vital and Health Statistics*, Series 10, No. 135, tables 1 and 2.

IMPACT OF MENTAL RETARDATION ON THE INDIVIDUAL AND THEIR FAMILY

Social Security and other independent data confirm that the number of children and adults with mental retardation sufficiently severe to require ongoing economic and social supports amounts to a million or more. (Of the frequently quoted figure of 6 to 7 million people at risk of being identified as retarded at some time in their lives, at least 85% are mildly retarded. In most cases, they should not be classed as having "catastrophic" lifetime requirements). What are the characteristics of this particular group that distinguishes it from others with long term disabilities, more particularly from those who become disabled as adults?

As already indicated, the medical conditions that underlie disability of early onset are quite distinct from the conditions associated with disability manifested later in life. Many of the causes operate during the perinatal period when myelination is not complete and the brain and central nervous system are most vulnerable to insult, thus exposing to risk the source of the most fundamental human functions of thought, feeling, communication, and voluntary control of bodily activities. This early impairment is likely to be pervasive in its interference with normal growth and development and with the acquisition of a serviceable education. In a practical sense it may mean that as an adult the individual never acquires a labor force attachment sufficient to establish entitlements through group insurance, compensation rights, and primary Social Security coverage. (Important as they are, CDB dollar awards are only a fraction of those awarded to

workers.) One indicator of the differential effect of disability on those with disability of early onset versus disabled workers lies in the observation that the annual "recovery" rate is only about 4 per thousand enrolled for CDB versus about 22 per thousand for SSDI.

An aspect of mental retardation that sets it somewhat apart from many other physical disorders is the extent to which many of the needed services and supports are psychological, social, or health-related, rather than what is traditionally termed medical. Training, guidance, supervision, protection and advocacy, and adjunctive services are more central than ongoing physician care, although adults with mental retardation need to be covered for intercurrent illness to the same extent as people who are not retarded.

However, in attempting to gain access to even standard health care coverage, people with retardation often face unwarranted and unfounded discrimination. Insurance companies have traditionally presumed that individuals with diagnoses of mental retardation, especially those with Downs Syndrome and other genetic conditions, present a higher risk. Exorbitant premiums and frequent denial of coverage have been the result.

The typical adult with severe retardation has few assets and little or no income; earnings, if any, are precarious at best. He is therefore often a candidate for public assistance, social services and health coverage under programs designed for public assistance recipients.

MEDICAID AND SOCIAL SERVICES FOR PEOPLE WITH DISABILITIES

Historically, coverage of medical costs has been regarded as a personal and familial liability in the same category as basic maintenance. In recent years the increased risks experienced have driven expansion of a private health insurance industry for people with enough income to pay the premiums. As societies have matured, and welfare systems have been developed to assure the survival and minimal well being of citizens unable to support themselves, health care costs have been factored in. Recently the medical component has been separately identified, although still linked to the basic maintenance component. The basic maintenance "welfare grant" to an individual or family covers the predictable costs of living and is discretionary within the dollar limits. The health coverage is triggered only by an expense "necessarily" incurred, and usually takes the form of a vendor payment.

When in 1974 the federal government assumed the primary fiscal and administrative responsibility for basic income maintenance for indigent aged and disabled individuals and couples, it left the administrative and considerable fiscal responsibility for the medical component with the states as part of a system designed for the AFDC population. The result has been great variability in covered services and consequent inequity. The objective of providing a uniform nationwide floor under assistance to the elderly and disabled has been obscured under state optional design of the medicaid programs. A broad definition of "health" which encompasses needs that are the consequence of a "medically determinable" condition or impairment

has brought some community services to a limited number of adults under the umbrella of medicaid waivers in some more progressive states.

Only some states have chosen to incorporate provisions that are truly responsive to the needs of people in different age groups who have disabilities. In particular, the needs of younger adults with disabilities are not well addressed; for example, needs for personal attendant services outside the home (for people living in their own homes), or sufficient in-home services in the morning or evening.

We are sure that the Committee is aware of the concerns about these and other instances of the "institutional bias" in medicaid and of the work disincentives that are associated with the criteria for eligibility as a disabled person. The latter have proved particularly troublesome for people with mental retardation for whom most available private sector employment pays low wages and is not characterized by sound health benefit packages; thus achieving employed status does not carry with it the same guarantees that most people associate with having a job.

The Social Services Block Grant is well designed to meet many of our goals for adults with mental retardation but its resources have not expanded significantly in recent years and have been largely spoken for already. It is no longer in any sense an individual entitlement program. For all these reasons, the costs of expanding community based services for adults with mental retardation has in recent years been born primarily by state

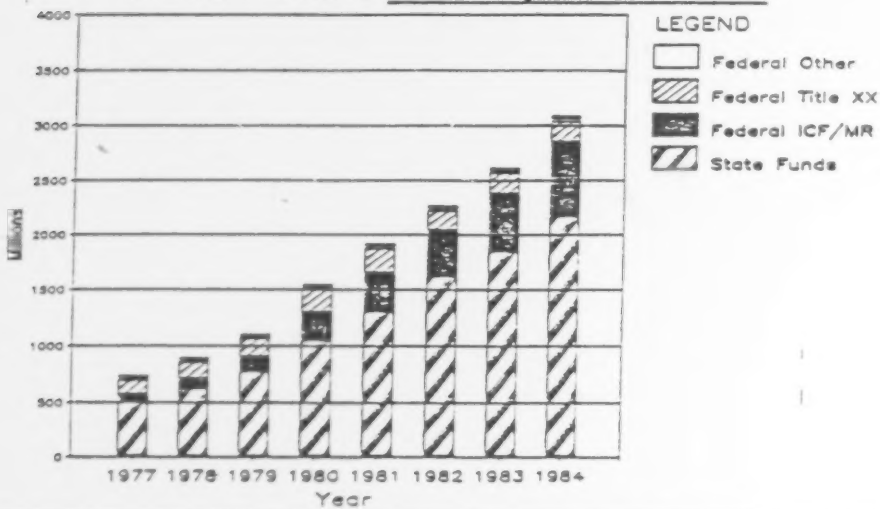
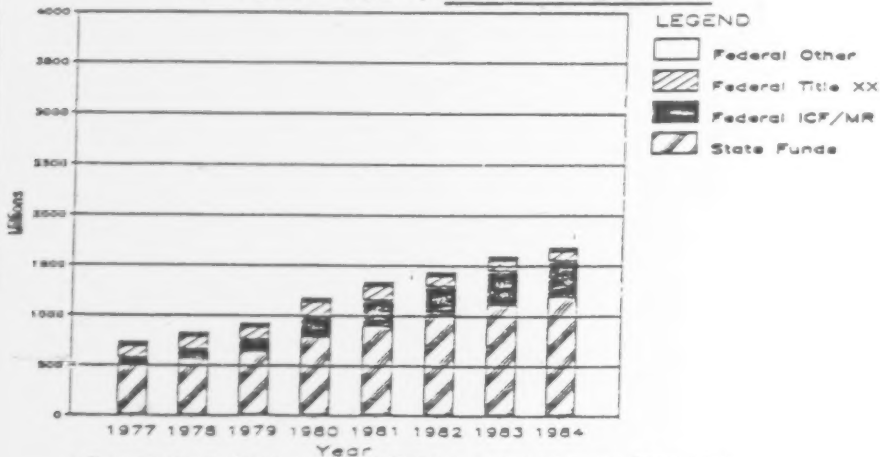
government, as illustrated by the following chart. The availability (since 1974) of a basic maintenance entitlement through SSI has complemented and fostered this development. Thus, the outlook for an active life has increased significantly in recent years for youths with moderate and severe mental retardation. Nevertheless, the fact remains that long term social and economic dependency is still the realistic outlook for most. This need for a life time of advocacy and social guidance that will extend beyond the expected life of the parent together with the probable absence of a capable and supportive spouse or children, presents a devastating prospect as the parents of a young child look ahead. "Who will care when I am gone?" is a perennial question.

THE FAMILY EXPERIENCE

Before the question of the future can be addressed one should ask "Who will care while I am still alive?" Today much emphasis is placed on increasing the family role in care. To the extent that a family is supported and enabled in exercising their parental role, this trend will bring a social good; to the extent that it becomes a cover for returning to the family additional sources of stress, new financial burdens, and a renewed sense of hopelessness with no light at the end of the tunnel, it can be a most insidious retrogression. Informal intermittent family oversight, with respite for the caregiver of the dependent disabled person, can make economic use of available family time and motivations; exacting a constant burden of continuous attendance can mean that a second and even a third life is put in jeopardy. Some

CHART III

UNITED STATES
MR/DD Expenditures for *Community* Services:
A Comparison of State & Federal Funding
FY 1977-1984, In Unadjusted Dollars

FY 1977-1984, In 1977 Dollars

* Excludes Income Maintenance (SSI/SSDI) & Special Education Expenditures
Source: Braggins, Hayes, & Kemp, Expenditure Analysis Project, SSCU, U of IL at Chicago, 1984, p. 10

years ago Michael Bayley conducted a study in Sheffield, England of the long term effects on caregiving family members, usually mothers, who had been tied for many years to the care of a disabled son or daughter. Clearly there had been at least two casualties in most of these homes.

Catastrophic effects of disability can be categorized under three broad headings: emotional/psychological, practical, and economic. One can consider each of them as it applies to the individual with a disability or to members of his family. The basic responsibility for coping with emotional stress lies with the actors; it may be alleviated or aggravated by others, but surrogation is not possible. To the extent (and it is considerable) that practical problems can be addressed by ingenuity within the family augmented by informal insightful neighborliness and community support, solutions can be sought close to home.

From a public policy perspective the first rule as it applies to the emotional and practical effects of disability on both the individual and family members must be to do no harm. Public policies and professional practice, fiscal or other, must be structured so as to avoid aggravating the emotional trauma or practical obstacles encountered by children and adults with disabilities and their families. In his compelling account of growing up with hemophilia Robert K. Massie, Jr. (1985) speaks of the enormous amount of time he spent waiting around in hospitals and offices for some brief treatment. Similar loss of time was experienced by his parents. This is an example of aggravation; it

also represents an economic loss (opportunity cost), even for a child, when he is kept from school. For Massie it was one of the many costs of medical care.

Opportunity costs, although usually measured in dollars or earnings lost, can also be measured in frustration of life goals and reduced quality of life for family members. Most professionals who deal with families recognize that serious long term indirect costs do cumulate within families giving direct care and that these multiply the more obvious effects of having little leisure time and being socially restricted. There is good reason to believe that many families with disabled children suffer a reduction in upward social and economic mobility, reducing not only the life time earnings of the breadwinners, but also curtailing career aspirations. Clearly such loss of productivity has consequences for society as well as for the individuals directly affected.

We in the ARC have direct evidence of this as we answer queries from service men stationed overseas who are evaluating their choices of location on return to the mainland. Choosing a community with the "right" community services may mean giving up a critical promotion. Our Association has historically sought social supports for families to retain their retarded children at home during minority. The spectacular decline (30 thousand between 1977 and 1982) in the school age population of public institutions is testimony that this is indeed the trend. We have equally supported the idea that disabled adults should be enabled

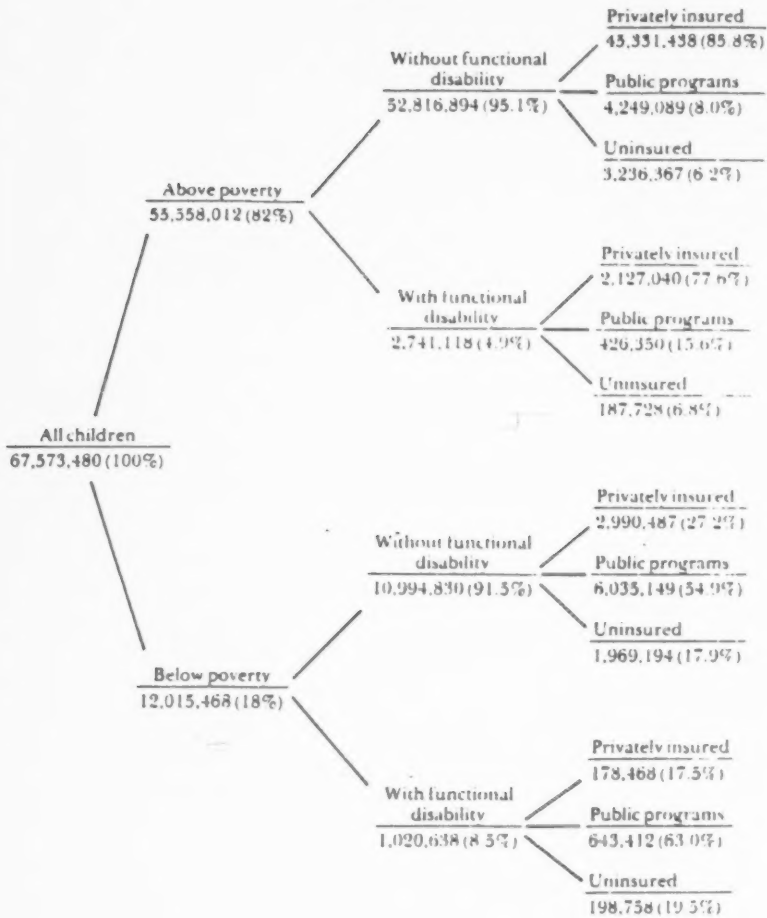
to move out of the parental home both for their own sakes and that of other family members. We have also recognized that it is reasonable to expect parents to provide financial support for a minor child with a disability to the same extent as for a normal child but, we also believe that society should share in the extraordinary and certainly in the catastrophic costs.

Since parents are not held liable for the support of their normal adult children, we believe that parents should not be held liable for the financial support of their adult disabled children. With the federalization of aid to the permanently and totally disabled in the SSI program in 1974, this principle, previously respected in some but not all states, was made uniform throughout the country in SSI but not medicaid. Title XIX Section 1902 (a)(1)(D) should be amended to conform by deletion of references to persons who are blind or disabled.

There remains to be considered the effect of 18 years of parental responsibility for costs that may be cumulatively catastrophic during childhood. A short term major catastrophe may wipe out a family's savings but when it is over they can start building again. With continuing disability and extraordinary annual costs, the middle class and even the well to do family is pushing the stone of Sysipus, and emerges in mid-life without the economic security proportionate to their effort and customary for their life stage. Thus they become part of the "at risk" population.

The Committee is undoubtedly familiar with the data shown in

CHART IV: 1979 Insurance Coverage for Affected Children, Birth Through Eighteen



Source: Data derived from U.S. Department of Health and Human Services health financing model. For details, see Bonhag and others, 1981.

Reprinted from: Butler, Budetti, McManus, and Newacheck

the accompanying table concerning insurance coverage for children. Poverty levels are usually expressed in terms of income. Public assistance and medicaid routinely are available only well below the poverty levels, but what such comparisons often do not reveal is the added deleterious effects of concurrent assets limits. While there may be some justification for expecting an elderly person applying for medicaid to draw on savings or even to transform investments into an annuity to pay for shelter or nursing care, rather than building up a windfall for heirs, the justice and efficacy of forcing a young family to draw down and maintain its assets at a penurious level, leaving nothing for contingencies or investment, or for climbing out of the well is surely questionable. We recommend raising the exemption level for assets for SSI families having more than one child. In addition we recommend allowing retention of income producing assets as long as they are producing countable income or, in the case of assets that do not produce income directly, imputable income.

At the same time we strongly support the idea that families should be encouraged to set aside funds when possible for the future use of their disabled children without imperiling their eligibility for essential services in the public domain.

SUMMARY

In our discussion we have attempted to better describe for the Committee the incidence of disabilities, mental retardation in particular; the changing and more functional ways of describing the impact of the disability on the individual and the consequent

diverse catastrophic needs and costs; the particular and multifaceted difficulties, including financial, experienced by the family; and existing health and related care coverage options. By necessity, the last have largely focused on public support mechanisms, although that is not meant to diminish our belief that all private care coverage options must be made to be effectively accessed by people with disabilities. In that regard, we wholeheartedly support the recommendations tendered by the Consortium for Citizens with Developmental Disabilities.

To the recommendations we have incorporated earlier in the text we add a recommendation that a study be conducted to further explore an HMO basis of health care provision to people with disabilities wherein the full range of necessary preventive as well as maintenance services would be available. This effort should be built on the demonstrations currently going on in Boston and elsewhere. Future enterprises could be supported by fees based on income with public subsidy to offset the "catastrophic" costs. There should be no income limitations for participation, either minimum or maximum. The plan should be designed to meet several concurrent needs: portable coverage that can be continued in periods of unemployment; predictable premiums paid regularly; coverage available to the self-employed, those part time of intermittently employed, and those who receive social security in excess of the SSI level; eligibility regardless of pre-existing conditions.

Thank you for this opportunity to appear before the Committee.

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**National
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Statement of

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and

Director, Employer-Provided Benefits Program

Heller Graduate School, Brandeis University

before

The Private/Public Sector Advisory Committee

on Catastrophic Illness

August 12, 1986

"The aggregate present value of William's future medical and rehabilitation expenses, including the hospital reserve fund and surgical treatment of the myositis, is from \$2,918,199 to \$3,209,378."
 ("Private economic report," for William X, 1983)

Thus concluded the economic report on a single head injury victim. The report also said "William has received aggressive rehabilitation treatment for 27 months. Although he still has severe cognitive and physical impairments he has responded well to the therapy regime. His progress to date has been extraordinary. There are no indications that his recovery will not continue but the pace, extent and duration of future progress cannot be precisely determined. There is a consensus among attending physicians that William will never be independent or employable."

William was 19 years of age at the time of his auto accident. He has had coma stimulation and rehabilitation for four years at an average cost of \$127,750 a year. He is one of some 70,000 persons severely head injured each year who require long term rehabilitation, in some cases costing as much as one million dollars per case.

Families of the head injury survivors are painfully aware of the need for catastrophic assistance. We know the stress, pain, suffering, dislocation and huge expense that follows that first tragic phone call. That call that always begins: "Mr. Bush: or Mrs. Whoever? Your son...your daughter...or wife or husband has been in a terrible accident." Six years and one month ago my wife, Jean, and I received that call from Houston, Texas. We were vacationing in Maine, two of our other sons were in

Pittsburgh, Pennsylvania. Our then 19 year old son, Patrick, had been in a very serious oil rig accident and was being flown to Herman Hospital. He was not supposed to be alive when we arrived. Today he continues to receive care and rehabilitation near our home in Massachusetts. He continues to make progress. He will never be the old Patrick but he is still improving.

We are extremely fortunate. Worker's Compensation and other insurance plus a legal settlement and personal funds have made it possible for us to spend nearly \$800,000 to date on acute care, coma stimulation, and rehabilitation for our son.

But Patrick Bush and, if I might, the James Brady's of this world, are the exception; the all too rare exception. Only one head injured person in twenty receives any rehabilitation today. Nineteen in twenty simply do not have funding.

The Committee on Trauma Research, Commission on Life Sciences, National Research Council and the Institute of Medicine report, Injury in America, states that head injury accounts for 500,000 hospitalizations each year. There are some 70,000 severe cases each year and some two thousand persons are left living in a persistent vegetative state each year. This is not an epidemic it is an unbridled cataclysm of monstrous human and financial import. When these seventy thousand persons are added to the annual twenty thousand spinal cord injuries, the thousands of stroke victims and the long term mentally ill you begin to define long term non-terminal catastrophic. But it must also be defined in realistic terms: long term rehabilitation and social services.

To complete the picture of head injury you should know that head injury has taken more American lives than all of America's wars since the founding of the Republic. It is the number one killer of persons under the age of 44 and kills more Americans under the age of 34 than all other diseases combined.

You should know that the incidence of head injury among our children is staggering. It is estimated that, yearly, 1 million children sustain head injuries. Of the one million children about 165,000 will be hospitalized.

Of these 165,000, approximately 1 in 10, or 16 in 17,000 children a year will have moderate to severe brain damage. In addition, many children without obvious disability--so-called "minor" head injuries--may show up in the classroom as learning disabled. In a recent survey of 1,500 special education students in Vermont, over 20 percent had a history of traumatic head injuries severe enough to have required hospitalization; of those listed as "emotionally disturbed," 40 percent had a history of head trauma. None of these children were listed as traumatically brain injured and none were receiving appropriate rehabilitation for traumatic brain injury because no one will pay.

Insurance available to cover the acute care and rehabilitation, under traditional health insurance policies, is extremely lacking in today's market as compared to those who suffer traumatic brain injury who are hurt on-the-job in a good Workers Compensation state. Under most health insurance policies there is a severe limitation as far as days and dollars available to meet the long term needs of the head injured population.

The vast majority of traumatic brain injuries, however, are the result of automobile crashes. Some estimate as high as 50% of the 70,000 severe cases. Therefore, the insurance programs of worker's compensation and other structured programs are not available. Few employers--private, public and not-for-profit--provide for extended rehabilitation.

In another case where a seventeen year old male was severely head injured it has been estimated that over the next 50 years, a not unreasonable life expectancy, someone will be required on a cash basis to expend \$50,242,820 for care, rehabilitation, and support. Very few, if any, individuals or families can afford this.

In any case, to state the numbers does not answer the parental question I am asked all across this nation: "Gerry, what's going to happen when we die?"

The numbers associated with severe head injury, the need in many cases to finance a lifetime of care, and the need for institutional development are truly worthy of the word "catastrophic." Without funding nothing will happen. Without funding there will never be an adequate answer to the question: "What happens when we die?"

In addition to the long time required for rehabilitation, another reason so few of the head injured are adequately served and that their care is so expensive is that head injury survivors are a relatively new disability. That is, surviving a severe head injury was almost unheard of ten years ago. Today, the odds are better than 50/50 that a severe head injury taken to a trauma

one center will survive. We all love and celebrate the story of James Brady, the President's press secretary and the newest NHIF spokesperson. Jim in all probability would not have survived had he sustained his head injury a decade ago. The same is true for our son, Patrick, and thousands upon thousands of others like him. Governments, employers, insurance companies and individuals have spent billions on acute care in almost total disregard of the "downstream" implications of those expenditures.

Furthermore, it is now abundantly clear that persons can show remarkable recovery over long periods of sustained rehabilitation measured in years rather than days and months. There is no question that the average number of days in rehabilitation to which many before me have testified reflects the absence of adequate funding more than the need for and efficacy of additional rehabilitation. There is no debate about the fact that the single number one reason for persons leaving rehabilitation is the termination of their funding source and the family's inability to sustain the huge cost.

Thus the need for catastrophic insurance to cover this new disability, as well as those who suffer from other catastrophic illnesses and injuries, and to sustain a program which will produce the maximum amount of rehabilitation. Again, referring to an extrapolation from the report Injury in America: Only one in twenty head injured survivors have access to or receive any rehabilitative services. The major contributing reason for this is lack of funding.

The National Head Injury Foundation commends you for your willingness to take upon yourselves the charge to look at this incredibly complex issue.

There will have to be a concerted effort on your part to pierce the rhetoric and the reality of the insurance and reinsurance industry. Perhaps your report can serve as a major contribution to the education of insurance companies and employers--public, private and not-for-profit--so that they can begin to understand exactly what is and what is not covered in the medical policies they make available to their employees. Remember the \$500,000 and \$1,000,000 individual maximum limits were established in the 1950s and have not been inflated since. Today it is easy to spend "to the limit."

It is nearly unconscionable that the vast majority of employer paid insurance does not cover rehabilitation. This is absolutely the case for the vast majority of HMO contracts. In this regard I recommend to you a careful rereading of the testimony of Dr. Steven Feinberg before this advisory committee. There is no shock on earth equal to that of a family facing charges upwards of one hundred thousand dollars for acute care and an equal amount each year for rehabilitation when they discovered that their employer provided insurance does not cover such services. There are stories upon stories upon stories in the media and even more among the head injured of such events and I am sure you have heard long testimony on this subject.

However, as we review catastrophic let us not forget the family that lived in the suburbs of the capitol city of this

reputedly great and powerful nation. When the jury found there was no liability and thus no funding the family was destitute. The mother of that head injured son returned home from court and took her son's life. She then took her own life.

There can be no question that the vast majority of health coverage is paid for by employers with or without employees sharing in those costs. It strikes us at the National Head Injury Foundation that our advocacy efforts, and yours, should be to create a system that would be distinguished at least by the following characteristics:

- 1) Any proposed system should be in addition to and not in lieu of current health benefits.
- 2) The system should reflect the complexity of the "downstream," post acute care setting. That is, coverage should provide for a wide variety of in-home, outpatient and residential rehabilitation, social services and skilled nursing care.
- 3) There should be a cognizance of the fact that a family should not need to pauper itself in order to receive assistance from a catastrophic fund.
- 4) The system should reflect the current pluralism of private, public, employer, government and individual contributions to the pooled risk-sharing.
- 5) Your view should include the poor, the full and part-time working population, the unemployed, the low and moderate paid, and current public program beneficiaries and it should

be a complement to an extended employer provided insurance system.

- 6) Your view should include a variety of tax incentives such as medical IRAs or medical 401(k)s so that individuals, employers and governments would participate in the development of the pool.
- 7) The best plan would include the largest number of participants in the risk-sharing.

There is no question that statistically those requiring catastrophic coverage are, as a percent of the total population, very small. There is no question that for that small percentage of the total population the effect is totally devastating financially and this only adds to the phenomenal psychological burden of grief, anger and hopelessness. The single most important element for this committee is to entertain the concept of a just, equitable and widely spread risk sharing.

Thank you.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Private/Public Sector Advisory Committee on Catastrophic Illness

August 12, 1986

Testimony of
Robert J. Demichelis &
Alice M. Demichelis
Reston, Virginia

Department of Health & Human Services
Private/Public Sector Advisory Committee on Catastrophic Illness

August 12, 1986

My name is Robert Demichelis and I am accompanied by my wife, Alice, who is a full-time unpaid volunteer for NHIF, talking to members of Congress and any representatives of government agencies who will listen. I am an attorney and have been employed in the life and health insurance business for over 25 years. We are residents of Reston, Virginia and are appearing here today in the capacity of parents of a head-injured child. You have heard previous testimony from Dr. Gerald Bush of the National Head Injury Foundation who has described the needs for catastrophic care due to all types of head injury. We would like to personalize the needs for catastrophic care for the "under 65" population.

Our son, Robert, who is now age 30, was injured in an automobile accident in February of 1980, over six and a half years ago. Prior to Robert's accident, he had completed college where he graduated with honors in accounting and finance and also was honored as a member of the Midwest All American Soccer Team for his junior and senior years. Robert sought employment in the Chicago area, where our family lived until moving here 10 years ago. He was hired by one of the "big eight" accounting firms. They had a good employee

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benefits program, but as I will show later, not good enough. He passed all four parts of the CPA exam at his first sitting. During his first year of work as a CPA, his performance was recognized by his employer, and he received a promotion, as well as salary increases. He continued playing soccer on an amateur basis and was invited to try out for professional teams. He was in excellent physical condition, when in February, of 1980, he had an automobile accident.

Robert and his roommate were returning from a basketball game at Northern Illinois University, where they had gone to school. Robert was driving his recently purchased automobile and was involved in a single car accident on the interstate highway on his return to Chicago. The left front of the automobile was demolished as a result of the collision with a concrete abutment. Robert's roommate was fortunate in receiving only a minor injury to his mouth and was released from the hospital after a short period of observation. Robert, however, was not so fortunate. Robert spent the next three weeks in a comma at Good Samaritan Hospital in Downers Grove, Illinois. He received excellent medical attention, the brain swelling was contained although his comma persisted over that three week period. During the next six weeks, he had to learn how to walk and talk again, even though he suffered no paralysis or other physical disability. After two months at Good Samaritan Hospital, we transferred Robert to George Washington University Hospital, Rehabilitation Ward by air

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medical evacuation, to be closer to home. I must point out that Robert's medical insurance did not pay for this transfer by airplane. After three weeks at George Washington University Hospital where he received physical therapy, speech therapy and other standard therapies for automobile accident victims, Robert was released home to our residence in Reston, Virginia. Most (80%) of Robert's medical bills were covered by his group health insurance through his employer, except of course his air med-vac from Chicago to Washington, DC. During Robert's hospitalization in Chicago and Washington, DC, he was treated by neurologists who identified his brain damage as a closed-head injury, with lower brain stem damage and frontal lobe damage. He was fortunate, as I stated before, that he had no other physical injury except a broken collar bone. Robert's therapies at George Washington Hospital did nothing to address the personality and cognitive disfunctions that resulted from his brain trauma. No recommendations were made for cognitive remediation to address his impaired learning and reasoning processes. He was just discharged home. He was advised to consult a vocational psychologist connected with George Washington University. Although this psychologist had a very fine reputation, we were very much surprised to learn that the psychologist had no experience or training that would help him in dealing with a CPA's occupational responsibilities.

In January of 1981 Robert returned to Chicago, on his own volition, to resume his responsibilities to his employer. His

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doctors gave no warning of what to expect. We did counsel his employer not to subject Robert to the same type of case load that he had previous to the accident. Over the next six months it became apparent to Robert's employer that he was having difficulties in dealing with clients and fulfilling his responsibilities, although Robert would never admit it. He received psychological counseling after his return to work but his performance continued to deteriorate, not only on the job, but also with his two roommates. In August 1981, Robert's employer unilaterally transferred him to their Washington, DC office, placing him on disability. His employer suggested strongly that he return to our house in Reston, Virginia and to resume contact with the medical professionals who had previously treated him. Since that time, over five years ago, Robert has not been employed in any capacity. In fact he has been medically determined to be "unemployable."

In February 1982, Robert's doctors advised him to enter the Psychiatric Institute of Washington, DC for treatment of his behavioral problems. After two months at the Psychiatric Institute, 100% of the psychiatric benefits (\$25,000) available to him under his employer's medical insurance policy were exhausted. The treatment Robert received at P.I. was totally inadequate and inappropriate to a person suffering a traumatic brain injury. In fact, two weeks after his discharge a catastrophic personality conflict resulted in Robert being committed to the Northern Virginia Mental Health Institute.

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In March 1983, Robert's disability income insurance ran out after the two year period due to his inability to perform his own occupation. Robert's employer informed him that his employment was terminated and that he had the option to convert his group medical insurance coverage, but admittedly on a limited basis. He was advised by his employer to apply for Social Security Disability Income benefits and that when social security benefits were awarded that his medical insurance would be reinstated. Alice and I assisted Robert in applying for the social security benefits, over his objections, since Robert's brain injury did not permit him to recognize the full extent of his disability, or the consequences of his failure to apply. In fact, on his application to social security, he stated that the primary cause of his disability was a minor knee injury, not the traumatic brain injury. Robert's application has been denied twice, and the matter is now in the hands of a local law firm. Under an act of Congress last year, his application is currently being re-reviewed. (He was injured six and a half years ago and hasn't been employable in any capacity for over five years; and still no decision by Social Security.) Meanwhile, Robert's medical insurance coverage has been terminated and his mother and I have paid all of his medical expenses. These costs do not reflect the family trauma or other expenses incurred due to Robert's aberrational behavior and impaired judgment, including several incidents with the law enforcement authorities. Numerous attempts at vocational

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rehabilitation through the efforts of the Virginia Department of Rehabilitation have been unsuccessful. On one occasion he was dismissed from a "sheltered workshop."

The treatment of traumatic brain injury is a long, elaborate and expensive process, as you have heard from Dr. Bush. I have attached to my testimony today some materials which elaborate on the extensive nature of the catastrophic care required for treatment for the brain injured. The first attachment is an address made on April 18, 1986 by Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, Department of Education. The second attachment is from the Virginia Head Injury Task Force Report submitted to Joseph Fisher, Secretary of Human Resources, State of Virginia in November, 1985. A third attachment is a California Statute (Ch. 1658) enacted in 1984 which is one example of state efforts to provide services to brain-injured adults.

Current insurance policies lack the comprehensive coverage essential to provide for the treatment of brain trauma. As I mentioned previously, Robert was involved in a single car accident, therefore there was no liability insurance involved to help offset any medical expenses. Robert's accident took place in Illinois, which does not have no-fault auto insurance. If he had been fortunate to have been involved in an accident in the state of Michigan, Robert's rehabilitation expenses

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would have been covered by no-fault auto insurance. (See attached articles from Consumer Reports and the Washington Monthly.) Robert's accident did not occur in an employment capacity therefore he was not covered under workers' compensation insurance. If he had been involved in a work-related accident, most of the rehabilitation expenses would have been mandated. If Robert had converted his group insurance coverage to individual coverage following his termination, the benefits so limited that even his employer would not recommend conversion. Of course, his disability income insurance does not cover the costs of rehabilitation. I am attaching to this statement copies of two reports submitted to the Insurance Task Force of the National Head Injury Foundation in January, 1986, which address the "Gaps and Problems in Insurance Coverages." Also attached is a statement on "Catastrophic Health Insurance Coverage, The Dilemma of Economic Responsibility" published in 1985.

What we are trying to say by setting out this past history of our son's traumatic injury, is that the issue of catastrophic health care is not an issue that relates solely to the elderly. There are thousands of individuals such as Robert, who are in the prime of their life, between the ages of 20 and 45, who have suffered traumatic brain injury and who have no insurance coverage to turn to for the costs of rehabilitation, or the costs of other medical expenses. Another example of the need for catastrophic care was reported

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in a series of articles in the Washington Post on June 8-11, 1986. It was the story of Brian Rife. His parents negotiation for rehabilitation coverage through an H.M.O. emphasizes the need for adoption of a national policy. Following publication of this series, Congressman Fortney (Pete) Stark, in a letter to the editor of the Post on June 23, 1986, stated the need very well. I quote:

"When an individual is injured, society should provide the support necessary to maximize that individuals return of function."

We believe that statement should be foremost in the mind of the Committee.

The issues of catastrophic care of a head injury are extremely complex. Our son is an adult and legally independent. My wife and I have no authority to make decisions on his behalf. We have attempted in the Virginia courts to obtain a limited guardianship over our son for the purpose of sending him to a rehabilitation treatment center for head-injured persons. We told the judge that we would remortgage our house (our major asset) to pay for the treatment, since Medicaid would not pay. Our efforts were unsuccessful because of the limits of existing Virginia statutes. During the past four years I have paid for Robert's out-patient therapy with neuro-psychologists and speech therapists who deal specifically with head-injured persons. My out-of-pocket costs have been close to \$25,000. These

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professionals have exhausted their abilities to deal with Robert as an out-patient. Their recommendation is for Robert to enter a residential treatment program for the head injured. They believe that a proper program will succeed in Robert's return as a viable member of society; probably not at a CPA, but certainly not as a welfare recipient. The medical profession had the ability to save Robert's life; bring him out of a coma; teach him to walk and talk. These expenses were covered by insurance. But that is as far as the insurance would go. Neither his employer or the insurance company attempted to bend the rules to pay for the expense of essential rehabilitative care. The simple solution was termination of employment; ship him home to his parents; and put him on welfare. Without us or a place to live, Robert would be roaming the streets with the other homeless population, until he would eventually end up at some mental institution which would undoubtedly fail to recognize that he was a helpless victim of traumatic brain injury.

Our involvement with the National Head Injury Foundation and the Virginia Head Injury Foundation has introduced us to hundreds of people who have had similar experiences that could be repeated to this Committee. We respectfully request that the Department of H.H.S. address the issue of catastrophic health care as it pertains to individuals like our son Robert who in the prime of their lives, have no place to turn. Medicaid and Medicare will not provide for his treatment;

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conversion of his employer's group health insurance will not provide for his treatment; disability income payments will not provide for his treatment. Worst of all, Robert's brain injury will not allow him to admit that he needs treatment. We present you with an example of need and plea for your compassionate consideration of alternatives for solving this complex health care issue. Thank you very much.

Attachments:

1. Remarks of Madeleine Will - April 18, 1986
2. Virginia Head Injury Task Force Report - November, 1985
3. California Ch. 1568, Statutes of 1984
4. Whatever Happened to No-Fault?
Consumer Reports - September, 1984
5. Whatever Happened to No-Fault?
The Washington Monthly - April, 1986
6. National Head Injury Foundation
Insurance Task Force Report - 1986
7. Catastrophic Health Insurance Coverage
The Dilemma of Economic Responsibility

REMARKS OF MADELEINE WILL
 ASSISTANT SECRETARY FOR SPECIAL EDUCATION
 AND REHABILITATIVE SERVICES
 U.S. DEPARTMENT OF EDUCATION
 NATIONAL HEAD INJURY FOUNDATION
 ANNUAL CONVENTION/BOARD MEETING:
 "BUILDING FOR THE FUTURE"
 APRIL 18, 1986

I am pleased to be with you for this conference. This is a special meeting because it brings together those who have had head injuries, their families as well as rehabilitation professionals. Together we have the opportunity to exchange ideas, to share personal and collective concerns, and to plan for future advances in the building of care and rehabilitation networks.

SCOPE OF THE PROBLEM

Traumatic brain injury (TBI) is a matter of great importance to all of us and I especially include the Office of Special Education and Rehabilitative Services. OSERS is very concerned about TBI and the fact that we must do better to help educate and rehabilitate all those affected with TBI.

The scope of the problem is large. The numbers of persons surviving traumatic brain injury are increasing significantly. Although estimates vary, by all accounts, traumatic brain injury is becoming a problem of major proportions. It is estimated that between 400,000 to 600,000 individuals suffer head injuries each year. Of these, between 30,000 to 50,000 a year are left with physical, intellectual or social impairments severe enough to prevent them from returning to their former levels of function.

The costs are enormous. Although data are sparse, surveys taken over 10 years ago report direct and indirect costs attributed to TBI at over four billion dollars. We know this figure has grown. This huge figure, also, does not reflect the loss of income or extended rehabilitation costs computed over the lifetime of a patient -- a truly staggering toll. The human costs are greater, in terms of permanent physical and mental problems.

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TBI is especially tragic for the young. In contract to stroke which primarily afflicts older adults, head injury strikes many persons during their formative years. The incidence of hospitalization for head injury in the United States is approximately 200 per 100,000 in young persons. Head injuries are most commonly the result of motor vehicle accidents. They usually involve young adults between the ages of 15 and 34 who are just at the beginning of their most productive years. Because the medical condition of the head injured person does not usually deteriorate past the acute care stage, the individual can be expected to live an additional 35 to 50 years. The impact on the individual, their families and society can therefore be considered long-term and significant.

GAPS

As I stated earlier, the number of persons affected by traumatic brain injury is increasing. As the result of advances in technology and surgical procedures, individuals who just a few short years ago would not have lived, are alive. However, our knowledge about traumatic brain injury and the services needed to help those with TBI are not keeping pace.

Although much work has been done to provide knowledge and improve services in the area of traumatic brain injury, many gaps still remain. This morning I would like to highlight just a few of the areas where gaps still exist in our knowledge about traumatic brain injury and in our service delivery systems and then mention some of the steps the Office of Special Education and Rehabilitative Services has taken and proposes to undertake to begin filling these. There are gaps in knowledge, in technology, in service delivery in professional preparation. Probably the most important gap is the gap between common sense and behavior. Want to concentrate on 4 areas. These are:

1. emergency medical services and acute care
2. comprehensive rehabilitation, including assessment, training and job preparation
3. transitional living and community reintegration
4. education.

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EMERGENCY MEDICAL SERVICES AND ACUTE CARE

As we view the gaps in our knowledge about TBI and our service delivery system, the logical place to begin is with emergency medical services -- the service provided by emergency teams and first responders to accidents.

One of the major problems in emergency care is our inability to identify the brain injury patient at the site. This, in turn, affects the ability to start the proper treatment. In most cases we just don't know how to provide definitive intervention at the time of injury.

There is also a lack of sophisticated communication for monitoring the patient in the field. With a heart patient, the technology is there and we know what to do. A similar technology is needed for treating the brain-injured individual.

Lack of physician involvement in teaching emergency care procedures to those providing emergency care is also in area of concern. There is a need for more in-service training in the initial treatment of TBI individuals on the part of acute care hospitals.

Gaps exist in the acute care phase, that period following the injury until the person is medically stable and ready for rehabilitation. One major gap is a lack of designated neuro-trauma centers. There are also gaps in our knowledge about clinical outcomes upon which we can base acute care treatment. We lack knowledge about how long acute care should last for the different types of brain injury.

Another gap is the lack of multi-specialty cooperation among the medical staff in areas such as neurosurgery, neurology, orthopedic surgery and rehabilitation medicine. Too often acute care medical personnel, such as neurosurgeons, lack proper rehabilitation understanding. This results in less than effective transition from acute care to rehabilitation.

COMPREHENSIVE REHABILITATION

Which leads me to the next phase of treatment and a second major area where we have gaps in our knowledge about TBI and our service delivery system. That area is comprehensive rehabilitation, including assessment, training and job preparation. Most serious here is a lack of specific knowledge of appropriate rehabilitation methods and techniques. In the rehabilitation phase, we know that

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the residual problems from head injury are many. They can seriously affect the cognitive, physical, and psychosocial areas of a person's life.

Cognitive problems may include reduced alertness; problems in concentration, learning, memory or problem-solving. We need to know more about effective techniques of cognitive retraining as part of the rehabilitation process.

Physical deficits from TBI can range from non-evident to severe. These include an inability to walk, pronounced gait impairments, labored speech, visual difficulties or poor balance. More research is needed on better ways of compensating for many of these problems.

Emotional problems resulting from TBI often seriously affect the person's dealings with his family, friends and colleagues. The ability to monitor, evaluate, and self-correct on-going behavior may also be frequently impaired. Social inappropriateness can make reintegration into society difficult. We need to better understand these problems and develop rehabilitation techniques to overcome these during the rehabilitative process.

Other impairments may be especially perplexing for families and for rehabilitation professionals. The rehabilitation client may appear to be totally engaged with the examiner and to test well, but at home the same person appears to be unmotivated, disorganized and unable to complete tasks, this problem accounts for a dropout rate of up to 90% in vocational rehabilitation programs for head injured people. This loss of function also may lead to the setting of inappropriate goals for rehabilitation. We need to be sure that we prepare for programs that can meet the needs of the injured client in effectively evaluating his or her own strengths and limitations.

In addition to these gaps in our knowledge, another problem in rehabilitation is that the rehab team often does not begin its intervention early enough. This is compounded by a breakdown in communication among the treating disciplines. Physical therapy, occupational therapy, rehabilitation psychology and recreational therapy each use different jargon and uncoordinated interventions. The rehabilitation process is further complicated by the breakdown between the rehab team and the family. Often the family is not told what is happening or what to do. This results in a lack of understanding of the behavioral problems of their family member.

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We also find a lack of coordination between the medical program and the psychosocial and vocational programs in the community. In addition, there is a lack of training of professionals regarding traumatic brain injury. VR counselors, vocational evaluators, social workers, and even insurance company personnel need to be better informed.

TRANSITIONAL LIVING AND COMMUNITY REINTEGRATION

A crucial outcome of the rehabilitation phase is the transition and reintegration into the community of brain-injured individuals, a third area in which we have gaps in our knowledge and service delivery. Presently there are many questions about resources in the community to provide appropriate services. Are we able to utilize the existing resources for services for TBI individuals? What kind of program is most appropriate: day program? halfway house? group home? community mental health services? Supported work and other transitional employment strategies, developed for other populations, need to be explored for TBI clients.

RECONCILIATION

There needs to be help for those assuming increasingly independent lives to ensure their ability to live and work in the community and to provide respite care for families. We need to explore whether or not the centers for independent living might be utilized to help those with traumatic brain injury. We need to look at strategies for providing such assistance.

EDUCATION

The fourth area in which we are experiencing serious gaps in our knowledge and ability to deliver appropriate services is that of education. There is a need for educational planning for all traumatically brain injured children to include advice from educators and rehabilitation personnel as well as M.D.'s. Evaluations in the school setting are difficult due to the complex problems associated with brain injury in children.

A critical need exists to help special education teachers who are required to provide educational services for these children, but who may not have the training or tools at hand. School counselors and psychologists need training as well. We need additional research on structuring appropriate educational programs as well as training for teachers. Also there are currently no

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certification standards for teachers working with brain injured children. Efforts should be made to establish them.

STEPS OSERS IS TAKING TO FILL GAPS

Having highlighted some of the areas in which information and service delivery gaps presently exist, it is important to outline some of the steps OSERS has taken and proposes to take to begin to fill some of these gaps.

As you are aware, about a year ago OSERS entered into a cooperative agreement with the National Head Injury Foundation. The purpose is to work together to help breach these gaps and try to meet the needs of TBI population. I recently received a report on our activities over the past year and impressive progress is being made.

Within OSERS itself, I've asked that a task force be formed to study brain injury issues and approaches to solving the problems using available OSERS resources. We have plans to continue and even increase the portfolio of research being conducted to the National Institute of Handicapped Research.

A variety of funding mechanisms are available including fellowships, research and development funds, field initiated research and innovative grants -- portions of which have the potential to be directed toward research in the area of traumatic brain injury. Paul Thomas of HIHR will speak to you later in greater detail about our research agenda.

EMERGENCY MEDICAL CARE AND ACUTE CARE

Some of the most dramatic advances in recent years from research have been in the area of emergency medical care. These improved techniques have resulted in the saving of far more lives than in the past. This growth has paralleled, in many ways, similar efforts for spinal cord injury treatment. Two OSERS components, the rehabilitation services administration and the National Institute of Handicapped Research, have been heavily involved in this effort.

We have learned much in our experience over the years with the model spinal cord injury system. The idea behind this was to provide selective, critical support to programs that already had a demonstrated commitment to providing services. As a result of the effective coordination and management of the model systems program, "rehabilitation" has been thoroughly integrated into

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emergency and acute medical care treatment and throughout a course of treatment. Also, because of the system's extensive data collection efforts, we know much more than we did before about the costs and course of rehabilitation.

It may be that the lessons learned from this system-building experience can be "translated" for brain injury treatment and rehabilitation care. There are a number of possibilities, such as the utilization of similar service delivery models for improvement of systems of care and for building independent living and community integration techniques.

We also plan to organize a separate subcommittee of the Interagency Committee on Handicapped Research. The purpose will be to continue the good rapport we have with the National Institutes of Health and to expand this work to other agencies in this field.

In addition, we are planning a meeting this May, in conjunction with the NHIF, as a preliminary step to help set a research agenda for an even larger meeting to be held in 1987 on traumatic brain injury research. In connection with these activities, we are also enlisting the help of the directors of brain injury research and training centers and SCI model systems. These meetings are part of our commitment to working cooperatively with NHIF, parents, professionals and brain-injured persons to help shape a research agenda that will begin to fill in some of the gaps already mentioned.

COMPREHENSIVE REHABILITATION

The research undertaken over the next few years will not only provide needed information on acute care but on rehabilitation as well. In addition to a research agenda, OSERS proposes to utilize the research and training centers to provide professional and continuing education in brain injury for the rehab discipline.

We plan to continue the work already begun to assist in developing state-wide plans for the provision of rehabilitation and special education services. Our work is based on our cooperative agreement with NHIF, CSAVR and NASDSE. Under consideration is the establishment of a national data base for brain injury, similar to the one in operation for spinal cord injury. And we plan to assist in the coordination of the medical and rehabilitation disciplines to meet TBI needs by periodically bringing together the appropriate professional groups on both a formal and informal basis.

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TRANSITION AND COMMUNITY REINTEGRATION

In the area of transition and community reintegration, we propose to explore the possibility of the involvement of the centers for independent living to assist brain injured persons in the activities of daily living.

We will explore ways in which our work in supported employment can be adapted to the needs of the brain injured. We also propose the development and enhancement of information and training materials and increased methods of dissemination.

EDUCATION

In this area of education, meetings with our Office of Special Education and NHIF are already underway. Last fall, Patty Guard, our Acting Director of Special Education Programs, participated in a NHIF seminar to discuss some of the issues raised earlier in my presentation.

Serious consideration will be given to ways in which OSERS can help assure proper training for special educators as they work with TBI individuals in the classroom. We will explore the question of certification as well.

CONCLUSION

The issue of traumatic brain injury is a vast, complex one -- an area about which we presently have as many questions as well have answers.

For its part, OSERS pledges to move ahead with an initiative in traumatic brain injury that will be comprehensive.

REPORT TO SECRETARY FISHER ON HEAD INJURY IN VIRGINIA

SECTION ONE

INTRODUCTION

Surviving traumatic brain injury confronts the individual, family and community with a complex and lengthy recovery (Figure I-1). Estimates of occurrences range from 200/100,000 to 610/100,000. The "silent epidemic" challenges the resources of families, communities and the Commonwealth to return quality of life to a group of citizens which will endure the consequences of medical, sensory-motor, language/cognitive and neurobehavioral disability. Presently, surviving head injury is a more likely outcome than death and will require the coordinated efforts of medical, governmental, religious and community resources if return to the "mainstream" of society is to occur. The head injured have become a recognizable clinical population with their own unique needs and requirements. The continuum of care necessary to maximize recovery has been more clearly identified as this growing population has pressed for services from various public, private and community-based facilities. The clear lack of case management has forced the patient and family to randomly seek services along the continuum of care. In some cases the skill and technical expertise are available. In other incidences, the services are not available due to the lack of knowledge, and/or the immaturity of the health delivery system for the head injured. In general, however, there is a lack of consistency in the distribution of existing service resources, both on a public and private basis. At best, even with availability of clinical skill, technical support, financial assistance and reliable access, the care and recovery of the head injured will require the precise and efficient

mobilization of resources in a time-wise progression, which allows a small margin of error, if overall outcome is to benefit the injured, their families as well as the local community.

The ultimate goal is to return the head injured to "functional independence." This is both a difficult and at times elusive task. However, currently there are specific knowledge-based skills, technical support needs, administrative and financial requirements that are recognizable as critical and necessary if the head injured in Virginia are to have the best opportunity to reach the ultimate goal.

The impact of head injury reaches far beyond the lives of the injured. The on-going efforts of families to gain care, as well as to guide recovery, has resulted in secondary complications and problems which in turn require added services. The family, too, goes through stages of recovery, but without the centrality of the injured persons needs and requirements. The overflow of problems to community life results in a management by crisis approach that accesses private and public resources in a chaotic and less than effective manner. Furthermore, the family and close relations to the injured struggle with the financial support questions regarding care services. The ill-defined and vague categorization of the head injured complicates their qualification for services. Both private coverage and public financial resources are confronted by families attempting to find support for the injured. Without comprehensive attention, local communities must endure the consequences of frantic demands made on conventional systems that can only partially serve.

Failure to coordinate existing skills and failure to develop needed service delivery components requires the state and local communities to randomly "contain" the problems of head injured. This report will attempt to describe the state of the head injured in Virginia. More importantly, however, this report will make known those actions which are realistic and applicable, here

and now, so as to reduce the consequences of head injury on the individual, family and the Commonwealth as a whole.

SECTION TWO

SECRETARY OF HUMAN RESOURCES FOR THE COMMONWEALTH OF VIRGINIA
TASK FORCE ON HEAD INJURY

EXECUTIVE SUMMARY

According to the mandate received from Secretary Joseph Fisher this Task Force has surfaced issues that:

- 1) describe the Nature of Head Injury in the State of Virginia
- 2) review and describe the Service Delivery Network in Virginia
- 3) describe Prevention approaches

THE NATURE OF THE PROBLEM

There are approximately 14,000 head injured in the State. The at-risk group for injury in Virginia is young males (62 percent) who are between 15-29 years of age (33 percent). Fifty percent of head injuries are related to automobile accidents; and auto accidents contribute to 70 percent of those resulting in coma. Drug and alcohol abuse contributes significantly to head injury especially in the age range of 15-29. Citizens 61 years of age and older are the second highest at-risk group, comprising 20 percent of the injured. Sixty-six percent of those injured will spend at least one to seven days in the hospital.

Those suffering head injury will endure the consequences of overlapping and prolonged disability due to medical/physical impairment, sensory-motor deficits, cognitive/intellectual loss, speech/language impairment, and neurobehavioral alterations.

THE SERVICE DELIVERY NETWORK

Those suffering moderate to severe injuries will require care including emergency medical services through intermediate rehabilitation and transitional outpatient care with educational, prevocational/vocational and housing resources needed at the upper end of the recovery continuum. Currently the Commonwealth lacks an integrated continuum of care for the initial care stages as well as poor coordination of acute/intermediate rehabilitation. Served by five level one shock trauma centers, the injured receive services from approximately 16 treatment facilities statewide. The interface with educational resources and vocational reentry training is poor and a general disruption in the continuum of care characterizes the head injured treatment. The lack of housing for the young adult and adult head injured is a significant gap in the overall return to functional independence. Services for family and those close to the injured are not formally developed or offered. Secondary problems to the family and/or the injured patient are absorbed in a random fashion by ill-prepared traditional resources such as mental health, education, and vocational agencies. Core service components are not standardly recognized as with other clinical populations. Furthermore, advocacy efforts are not widely known either by the injured individual's family or treating facility.

The disorganized resources and the failure to delineate core treatment elements has had its influence on the efficacy of petitioning for private and public third party coverage for services. There is a need for statewide examination of coverage issues. The individual or community treatment facility lacks the power base necessary to adequately influence the policy affecting financial support for the lengthy recovery period ahead of the head injured.

PREVENTION ISSUES

The majority of head injuries can be prevented, but the necessary steps to accomplish this are entangled with financial, political and business issues that make practical solutions elusive. Issues affecting driving licensure, motor vehicle operation, interscholastic sports, and environmental barriers/architecture would all be implicated for change.

Techniques of Persuasion, Law and Regulations do not have the expected penetration into "at-risk groups" that one would predict. Consequently, Automatic Protection approaches have emerged as the most effective methods. The emphasis on motor vehicle occupant protection has received much deserved attention. Air bag use has, when compared to seat belt methods of safety, found particular favor as the means of automatic protection. Arguments regarding cost factors do not seem to withstand close examination. Motor vehicle design and highway design could further be approached with automatic protection methods in mind. Motorcycle and recreational vehicle use also requires close attention as far as automatic protection could apply.

Envisionary approaches would be required to reduce the head trauma due to firearms, and falls as well. A sizable number of sporting accidents which are due to some form of collision/contact leave their effect on central nervous system function. For example, 19 percent of high school football players reported concussion-related loss of consciousness and/or loss of awareness. These episodes can be followed by a six to nine month ^{period of} persistent concussion symptoms. Aggressive "sport medicine" training which influences coaching and team efforts are implicated in this problem. In general, prevention must target "at-risk groups" and penetrate them in order to maximize initial efforts.

PRIORITY RECOMMENDATIONS

1. Develop a legislative/executive entity similar to the Long Term Care Council, which has representation from relevant state agencies, private service interests, and advocacy organization to promote and monitor the execution of recommendations put forth by this Task Force.

This group would serve to further the work of the existing body, but with legislative and executive knowledge and purpose to serve the development of comprehensive, coordinated systems for the prevention and service delivery needed components for recovery from head injury.

2. Develop and establish through appropriate funding a Neuro-trauma Rehabilitation System (NRS) that proceeds from a core group of medical schools in Virginia to include regional facilities that will contribute and adhere to a standard treatment approach, as well as promote demographic studies and research so as to advance educational efforts throughout the commonwealth.

This NRS will serve a research and treatment development need as well as provide a greatly needed case management role that would ensure the continuum of care so important to the recovery from head injury. This NRS, in time, will include statewide representation and penetration so that regional care and community-based care can be of a high quality throughout the commonwealth.

3. Promote and advance vocational training projects modeled after the Northern Virginia Project for the Head Injured. As part of this increased vocational preparation for the head injured, Supported Employment funding would be allocated so as to maximize employment reentry.

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4. Support efforts of VHIF to develop alternative housing for the head injured. This effort should include an active promotion of recommendations made in Joint Subcommittee Monitoring Long Term Care and the Fisher/Diener Committee on Housing for The Disabled.
5. Work with the Department of Education to: train educators regarding the consequences of mild, moderate and severe head injury and inform local educational systems of community-based expertise on head injury that can provide resources to schools developing Individual Educational Plans.
6. Create a Catastrophic Fund modeled after existing state programs.
7. Have the above mentioned legislative/executive body promote statewide investigation of private and public third party payment policies and standards for the care of head injured.
8. Promote Automatic Protection prevention approaches through legislative and appropriate state agencies to include:
 - a. Passive restraint and automobile occupant safety needs
 - b. Sport medicine education and prevention in sports
 - c. Environmental management strategies for firearms, and fall related injuries.

**MENTAL HEALTH—SERVICES FOR PERSONS WITH
BRAIN DAMAGE OR DEGENERATIVE
BRAIN DISEASE—RESPITE CARE**

Assembly Bill No. 2913

CHAPTER 1658

An act to repeal and add Chapter 4 (commencing with Section 4330) of Part 2 of Division 4 of the Welfare and Institutions Code, relating to mental health, making an appropriation therefor, and declaring the urgency thereof, to take effect immediately.

[Approved by Governor September 30, 1984. Filed with
Secretary of State September 30, 1984.]

LEGISLATIVE COUNSEL'S DIGEST

AB 2913, Agnos. Mental health.

Under existing law, the Director of Mental Health is required to establish a pilot project for brain-damaged persons for one year to be conducted by contract with an appropriate nonprofit community agency.

This bill instead would require the director to contract with a nonprofit community agency meeting certain requirements to act as the Statewide Resources Consultant and to also contract with nonprofit community resource agencies to establish regionally based resource centers to provide specified services to brain-impaired adults.

This bill would appropriate \$1,700,000 for the 1984-85 fiscal year for the purpose of the bill.

This bill would take effect immediately as an urgency statute.

Appropriation: yes.

The people of the State of California do enact as follows:

SECTION 1. Chapter 4 (commencing with Section 4330) of Part 2 of Division 4 of the Welfare and Institutions Code is repealed.

SEC. 2. Chapter 4 (commencing with Section 4330) is added to Part 2 of Division 4 of the Welfare and Institutions Code, to read:

**CHAPTER 4. SERVICES FOR PERSONS WITH BRAIN DAMAGE OR
DEGENERATIVE BRAIN DISEASE**

4330. The Legislature finds all of the following:

(a) That state public policy discriminates against adults with brain damage or degenerative brain disease, such as Alzheimer's disease, hereinafter called "brain impairments."

(b) That the Legislature has declared state public policy and accepted responsibility to ensure that persons under the age of 18 years who are "developmentally disabled" pursuant to Division 4.5

(commencing with Section 4500), receive services necessary to meet their needs, which are often similar to those of persons who suffer from brain impairments.

(c) That persons over the age of 18 who sustain brain impairment have a variety of program and service needs for which there is no clearly defined, ultimate responsibility vested in any single state agency and for which there are currently a number of different programs attempting to meet their needs.

(d) That the lack of clearly defined, ultimate responsibility has resulted in severe financial liability and physical and mental strain on brain-impaired persons, their families, and caregivers.

(e) That terminology and nomenclature used to describe brain impairments are varied and confusing, in part because of different medical diagnoses and professional opinions, as well as differences in terminology used by the various funding sources for programs and services. Uniformity is required in order to ensure that appropriate programs and services are available throughout the state to serve these persons.

(f) That the term "brain damage" covers a wide range of organic and neurological disorders, and that these disorders, as identified below, are not necessarily to be construed as mental illnesses. These disorders include, but are not limited to, all of the following:

(1) Progressive, degenerative, and dementing illnesses, including, but not limited to, presenile and senile dementias, Alzheimer's disease, multiinfarct disease, Pick's disease, and Kreutzfeldt-Jakob's disease.

(2) Degenerative diseases of the central nervous system that can lead to dementia or severe brain impairment, including, but not limited to, epilepsy, multiple sclerosis, Parkinson's disease, amyotrophic lateral sclerosis (ALS), and hereditary diseases such as Huntington's disease.

(3) Permanent damage caused by cerebrovascular accidents more commonly referred to as "strokes," including, but not limited to, cerebral hemorrhage, aneurysm, and embolism.

(4) Posttraumatic, postanoxic, and postinfectious damage caused by incidents, including, but not limited to, coma, accidental skull and closed head injuries, loss of oxygen (anoxia), and infections such as encephalitis, herpes simplex, and tuberculosis.

(5) Permanent brain damage or temporary or progressive dementia as a result of tumors (neoplasm), hydrocephalus, abscesses, seizures, substance toxicity, and other disorders.

(g) That brain damage frequently results in functional impairments that adversely affect personality, behavior, and ability to perform daily activities. These impairments cause dependency on others for care and decisionmaking. The manifestations of brain damage include impairments of memory, cognitive ability, orientation, judgment, emotional response, and social inhibition. Brain damage can strike anyone regardless of age, race, sex, occupation, or economic status.

(h) That Family Survival Project for Brain-Damaged Adults of San Francisco, a three-year pilot project established pursuant to

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former Chapter 4 (commencing with Section 4330), has demonstrated that the most successful, cost-effective service model is one which allows a nonprofit community agency to provide a full array of support services to families that have a member who suffers from a brain impairment. This agency provides direct services, coordinates existing resources, and assists in the development of new programs and services on a regional basis.

(i) That respite care services provide a combination of time-limited, in-home, and out-of-home services which significantly decrease the stress of family members and increase their ability to maintain a brain-impaired person at home at less cost than other alternatives. This ability is further increased when complemented by case planning, care training, and other support services for family members.

(j) That, since 1977, the State Department of Mental Health has attempted to identify service gaps and determine a cost-effective, feasible approach to funding and providing services to brain-damaged adults, their families, and caregivers. That department has the experience of offering more in the continuum of programs and services than any other state agency and is willing to continue in the lead state agency capacity.

(k) That providing services to brain-impaired adults, and to their families and caregivers, requires the coordinated services of many state departments and community agencies to ensure that no gaps occur in communication, in the availability of programs, or in the provision of services. Although the services may include mental health interventions, they cannot be met solely by services of the State Department of Mental Health.

4331. As used in this chapter:

(a) "Brain damage," "degenerative brain diseases," and "brain impairment" mean significant destruction of brain tissue with resultant loss of brain function. Examples of causes of the impairments are Alzheimer's disease, stroke, traumatic brain injury, and other impairments described in subdivision (f) of Section 4330.

(b) "Brain-impaired adult" means a person whose brain impairment has occurred after the age of 18.

(c) "Respite care" means time-limited substitute care or supervision in support of the caregiver for the purposes of providing relief from the stresses of constant care provision and so as to enable the caregiver to pursue a normal routine and responsibilities. Respite care may be provided in the home or in an out-of-home setting, such as day care centers or short-term placements in inpatient facilities.

4332. The director shall administer this chapter and establish standards and procedures, as the director deems necessary in carrying out the provisions of this chapter. The standards and procedures are not required to be adopted as regulations pursuant to the Administrative Procedure Act (Chapter 3.5 (commencing with Section 11340) of Part 1 of Division 3 of Title 2 of the Government Code).

4333. The director shall do both of the following:

(a) Contract with a nonprofit community agency meeting the requirements of this chapter to act as the Statewide Resources Consultant, to be selected through a bid procedure.

(b) With the advice of the Statewide Resources Consultant and within four years from the effective date of this chapter, contract with nonprofit community resource agencies, selected in a manner determined by the director, to establish regionally based resource centers in order to ensure the existence of an array of appropriate programs and services for brain-impaired adults. The resource center shall place a high priority on utilizing community resources in creating opportunities for families to maintain a brain-impaired adult at home when possible and in other community-based alternatives when necessary.

4334. The Statewide Resources Consultant shall do all of the following:

(a) Serve as the centralized information and technical assistance clearinghouse for brain-impaired adults, their families, caregivers, service professionals and agencies, and volunteer organizations.

(b) Work closely and coordinate with organizations serving brain-impaired adults, their families, and caregivers in order to ensure, consistent with requirements for quality of services as may be established by the director, that the greatest number of persons are served and that the optimal number of organizations participate.

(c) Develop training packages which are appropriate for a variety of persons, including, but not limited to, all of the following:

(1) Families.

(2) Caregivers and service professionals involved with brain-impaired adults.

(3) Advocacy and self-help family and caregiver support organizations.

(4) Educational institutions.

(d) Provide service and program development consultation to resource centers and to identify funding sources which are available.

(e) Assist the appropriate state agencies in identifying and securing increased federal financial participation and third party reimbursement, including, but not limited to, Title XVIII (42 U.S.C. Sec. 1395 et seq.) and Title XIX (42 U.S.C. Sec. 1396 et seq.) of the federal Social Security Act.

(f) Conduct public social policy research based upon the recommendations of the Director of Mental Health.

(g) Assist the director, as the director may require, in conducting directly, or through contract, research in brain damage epidemiology and data collection, and in developing a uniform terminology and nomenclature.

(h) Assist the director in establishing criteria for, and in selecting resource centers and in designing a methodology for, the consistent assessment of resources and needs within the geographic areas to be serviced by the resource centers.

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(i) Conduct conferences, as required by the director, for families, caregivers, service providers, advocacy organizations, and educational institutions in order to enhance the quality and availability of high-quality, low-cost care and treatment of brain-impaired adults.

4335. In choosing an appropriate nonprofit community agency to act as the Statewide Resources Consultant, the director shall give priority to an agency which meets both of the following:

(a) An agency which has a proven record of experience in providing information, technical assistance and direct services to adults with all types of brain impairments, their families, and caregivers.

(b) An agency which includes family members and caregivers of brain-impaired adults on its board of directors.

4336. (a) The Statewide Resources Consultant shall submit progress reports on its activities as required by the director. These reports shall include, but not be limited to, a summary and evaluation of the activities of the resource centers. Client, caregiver, service, and cost data shall be provided for each operating resource center.

(b) The department, in consultation with the Statewide Resources Consultant, shall report to the Legislature by annually on the effectiveness of the resource centers. The report shall be submitted within three months after the end of each calendar year. The evaluation shall include, but not be limited to, all of the following:

(1) A comparative assessment of the costs and effectiveness of each type of service or combinations of services provided.

(2) An assessment of the nature and extent of the demand for services which provide respite, and an evaluation of their success in meeting this demand.

(3) An analysis of the effectiveness of the program in deterring the institutionalization of brain-impaired adults, allowing caregivers to maintain a normal routine, and promoting the continuance of quality care for brain-impaired adults.

(4) Recommendations for ensuring that unmet needs of brain-impaired persons and their families are identified and addressed with appropriate programs and services.

4337. The resource centers shall serve all of the following functions:

(a) Provide directly or assist families in securing information, advice, and referral services, legal services and financial consultation, planning and problem-solving consultation, family support services, and respite care services, as specified in Section 4338.

(b) Provide centralized access to information about, and referrals to, local, state, and federal services and programs in order to assure a comprehensive approach for brain-impaired adults, their families, and caregivers. Nothing in this chapter shall prohibit access to services through other organizations which provide similar programs and services to brain-impaired adults and their families, nor shall other organizations be prevented from providing these programs and services.

(c) Assist in the identification and documentation of service needs and the development of necessary programs and services to meet the needs of brain-impaired adults in the geographic area.

(d) Cooperate with the Statewide Resources Consultant and the Director of Mental Health in any activities which they deem necessary for the proper implementation of this chapter.

(e) Work closely and coordinate with organizations serving brain-impaired adults, their families, and caregivers in order to ensure, consistent with requirements for quality of services as may be established by the director, that the greatest number of persons are served and that the optimal number of organizations participate.

4338. Agencies designated as resource centers by the director after consultation with the Statewide Resources Consultant shall include in their governing or advisory boards, or both, as required by the director, persons who are representative of the ethnic and socioeconomic character of the area served and the client groups served in the geographic area.

Criteria to be used in selecting resource centers shall include, but not be limited to, the following:

(a) Fiscal stability and sound financial management, including the capability of successful fundraising.

(b) Ability to obtain community support for designation as a resource center with the region recommended by the director.

(c) Demonstrated ability to carry out the functions specified in Section 4337, particularly in delivering necessary programs and services to brain-impaired adults as defined in subdivision (c) of Section 4330.

4338.5. Resource centers shall carry out the functions specified in Section 4337 through the administration and provision of programs and services that reflect the most progressive care and treatment alternatives available for brain-impaired adults, their families, and caregivers. These programs and services may be provided directly or through the establishment of subcontracts as specified in their contract and within the limitations imposed by budget appropriations. The department shall make efforts to achieve a goal that not less than 90 percent of the funds appropriated through contracts with resource centers shall be utilized for direct services, including, but not limited to, the following:

(a) Information, advice, and referral and family support services, including, but not limited to, all of the following:

(1) Information and counseling about diagnostic procedures and resources.

(2) Long-term care planning and consultation.

(3) Legal and financial resources, consultation, and representation.

(4) Mental health interventions.

(5) Caregiving techniques.

(b) Respite care services through the flexible and creative use of existing local resources, including, but not limited to, all of the following:

(1) In-home care.

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- (2) Adult day health and social day care services.
- (3) Foster and group care.
- (4) Temporary placement in a community or health facility.
- (5) Transportation.

(c) Training and education programs for brain-impaired adults, their family members, caregivers, and service providers that will lead to the high-quality, low-cost care and treatment of service clients.

4339. The director shall establish criteria for client eligibility, including financial liability, pursuant to Section 4339.5. However, persons eligible for services provided by regional centers or the State Department of Developmental Services are not eligible for services provided under this chapter. Income shall not be the sole basis for client eligibility. The director shall assume responsibility for the coordination of existing funds and services for brain-impaired adults, and for the purchase of respite care services, as defined in subdivision (c) of Section 4331 and described in subdivision (b) of Section 4336, with other departments that may serve brain-impaired adults, including the Department of Rehabilitation, the State Department of Health Services, the State Department of Social Services, the State Department of Developmental Services, the Department of Aging, and the State Department of Alcohol and Drug Abuse.

4339.5. Persons receiving services pursuant to this chapter may be required to contribute to the cost of services depending upon their ability to pay, but not to exceed the actual cost thereof. The criteria for determining client contributions which may be paid to the resource center under this chapter and standards for their utilization by the resource center in developing new programs and services shall be determined by the director after consultation with the Statewide Resources Consultant.

4339.6. In considering total service funds available for the project, the director shall utilize funding available from appropriate state departments, including, but not limited to: the State Department of Health Services, the State Department of Social Services, the Department of Rehabilitation, the Department of Aging, and the State Department of Alcohol and Drug Abuse. The director in conjunction with the Statewide Resources Consultant shall coordinate his or her activities with the implementation of the Torres-Felando Long-Term Care Reform Act (Chapter 1435, Statutes of 1982) in order to further the goal of obtaining comprehensive, coordinated public policy and to maximize the availability of funding for programs and services for persons with brain impairments.

SEC. 3. The sum of one million seven hundred thousand dollars (\$1,700,000) is hereby appropriated for the 1984-85 fiscal year from the General Fund to the State Department of Mental Health for the purposes of this act. Funding in subsequent years of programs under this act is subject to the annual appropriation of funds in the Budget Act.

SEC. 4. This act is an urgency statute necessary for the immediate preservation of the public peace, health, or safety within

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the meaning of Article IV of the Constitution and shall go into immediate effect. The facts constituting the necessity are:

In order that certain greatly needed services to brain-impaired adults may be provided at the earliest possible time, it is essential that this act go into immediate effect.



Robert Demichelis was returning home from a basketball game at Northern Illinois University three years ago when he dozed off at the wheel. His Datsun 200SX bounced off a guard rail and struck a concrete divider in the middle of Interstate 5. His head rammed the windshield.

Now 25, Demichelis requires speech therapy four times a week. He can't hold a job because the accident virtually destroyed his ability to reason and make judgments. Health insurance helped pay for his medical bills, but his family has had to pay for all of his rehabilitation treatments—some \$15,000 worth so far. The family is currently paying \$1400 a month, and no insurance money is coming in.

Faith Ann Glynn was riding a bicycle near her home in Midland, Mich., when a car struck her from behind and catapulted her into a cement bridge. The 13-year-old girl needed two brain operations, and doctors didn't expect her to live. For two years, she lived in nursing and rehabilitation centers.

Today, five years after the accident, Faith Ann is living a near-normal life. She attends Midland High School, loves poetry, swims, and even rides her bike again. She functions almost at her age level. Her family has paid nothing for her medical care and rehabilitation treatment. The family's auto-insurance company has borne the entire cost, which has so far amounted to more than \$150,000.

Both these accidents were emotionally traumatic for the families involved. But one accident produced financial trauma as well, while the other left the family financially unscathed. The difference was simply a matter of which state the victims lived in when their accidents occurred.

Demichelis had the bad luck to live in Illinois, a state that has old-fashioned automobile insurance under the tort liability system. In tort states, car owners buy auto insurance primarily to protect themselves from lawsuits in case they or members of their family cause an accident that injures someone else. When drivers, passengers, or pedestrians are injured, they must rely on other types of insurance to pay their bills—or sue.

Demichelis could sue no one, since there was no one to hold liable for his accident. His employer's health-insurance policy paid for most of his hospital expenses, and his group disability policy provided some benefits for a couple of years. But that was it. His auto-insurance policy paid nothing for his care.

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Faith Ann Glynn was injured in Michigan, a state that has the best no-fault auto insurance law in the country. Under Michigan's no-fault system, the right to sue is limited. Car owners must buy coverage that reimburses them for their own medical and rehabilitation expenses and for lost wages. It also covers members of their families hurt in car accidents—even if they are in someone else's car, or traveling out of state, or as in Faith Ann Glynn's case, on a bicycle or walking.

The no-fault policy on Faith Ann's family's 1973 Buick paid all of the child's medical and rehabilitation expenses. Under Michigan's law, the insurance company pays these expenses for the life of the victim. Had her mother sued the driver of the car, she probably would have collected very little. The driver carried minimum liability insurance and lived in a rented trailer. Under the tort system, Faith Ann would probably have received no more than \$20,000—a small fraction of the amount her family's insurance company has already spent for her care.

The striking contrast between the

Demichelis case and the Glynn case symbolizes the difference between the traditional tort approach and the no-fault approach. In light of some manifest advantages for the no-fault system, it may seem surprising that only about half the states have yet adopted any form of no-fault auto insurance. What's more, many states that nominally have no-fault have some half-hearted version of it instead of the full-scale version that exists in Michigan.

The need for no-fault

The model for no-fault insurance plans was workers' compensation insurance, which pays benefits to an injured worker without regard to whether the worker or the company caused the accident—and therefore without the need for litigation over who was at fault. In the mid-1960's, Robert Keeton, then a Harvard law professor, and Jeffrey O'Connell, then a professor of law at the University of Illinois, proposed extending the no-fault idea to auto insurance.

Shortly afterward, the U.S. Department

of Transportation (DOT) studied the automobile liability system in the U.S. and found it sorely wanting. The system was ineffective, overly costly, and slow, the DOT concluded. Often, seriously hurt victims lacked the money to pay their medical bills; they depended for compensation on proving in court that the other driver was at fault and should pay.

It could take years to settle a case—and even then injured victims played the legal system's version of roulette. If they sued a driver with no assets and little insurance, they might get nothing. But if they sued a well-insured or wealthy driver, they might hit the jackpot—including large awards for "pain and suffering."

The DOT study showed that in most cases victims who suffered large economic losses were not fully compensated, while those with minor injuries sometimes received amounts several times greater than their actual expenses. Drivers such as Demicheli, who were hurt in single-car accidents, usually got nothing.

The liability system discouraged rehabilitation and overburdened the courts and in some cases siphoned into lawyers' pockets money that could have been used to rehabilitate crash victims. Under the tort system, lawyers commonly took cases on a contingency basis—that is, they'd collect a portion of the award, usually one-third, if they won. In some cases, of course, a lawyer helped a victim gain a large settlement.

If lawyers were cut out of the system, Keeton and O'Connell argued, more money could go to the seriously injured, and it could go there faster. Under no-fault, you wouldn't need a lawyer to get your bills paid. In the early 1970's, a movement toward some type of no-fault system swept through state legislatures. But state trial lawyers' associations and individual trial lawyers lobbied hard to prevent no-fault laws. They were largely successful either in blocking no-fault laws or in so watering them down as to make the new system barely less litigious—and, in some cases, even more expensive—than the old.

"If we look at the laws, we can clearly see the fingerprints of the trial lawyers on them," says Robert Pike, a vice president for Allstate Insurance Co. In states where lawyers managed to preserve most of their business, no-fault hasn't kept its promises.

What makes a good law?

A good no-fault law balances payment of benefits with restrictions on lawsuits. If a state wants insurance companies to offer generous no-fault benefits at an affordable price it must restrict the number of lawsuits. Otherwise, no-fault benefits are grafted on top of the old tort system. Then the savings from reduced liti-

gation aren't enough to pay for the new benefits, and the insurance companies must substantially raise premiums.

There are few good no-fault laws. As we've noted, Michigan has the best. Accident victims such as Faith Ann Glynn have all their medical and rehabilitation expenses paid by their own insurance company. If an injured person can't work, the law requires insurers to pay lost wages up to \$2252 a month for a period of three years. Families of victims killed in auto accidents can also collect

"If we look at the laws, we can clearly see the fingerprints of the trial lawyers on them," says Robert Pike, a vice president for Allstate.

the lost-wage benefit, in the form of survivors' benefits. The Michigan law significantly restricts lawsuits: victims can sue only if the accident results in death, permanent disfigurement, or serious impairment of body function.

New York and Florida also have good laws. New York provides up to \$50,000 worth of medical, wage-loss, and rehabilitation benefits. Florida provides up to \$10,000. Restrictions on lawsuits are similar to Michigan's. Victims can sue only if they are seriously injured; their heirs can sue in the event of their death. These so-called "descriptive thresholds," which allow victims to sue only if they meet a serious-injury test, have turned out to be the most effective means of balancing the right to sue against the benefits provided by a no-fault system.

Descriptive thresholds are distinguished from monetary thresholds. New York and Florida had earlier used a dollar ceiling based on a victim's medical expenses. New York, for example, used to allow victims to sue if they had more than \$500 in medical bills. In Florida victims could sue if bills totaled \$1000.

Dollar thresholds encouraged abuses—inflated doctor bills, taked injuries, and the like. "With a \$500 threshold it was no challenge to become seriously injured in New York," says John Reiersen, assistant property-and-casualty chief of the New York Insurance Department. Since lawsuits weren't effectively eliminated, costs skyrocketed. Insurance companies were paying for a lot of lawsuits and for the required no-fault benefits as well.

Insurance rates rose about 37 percent a year in New York from 1974 to 1978.

The New York state legislature replaced the dollar threshold with a descriptive one in 1977, and placed caps on fees charged by doctors and hospitals for treating auto-accident victims. Lawsuits dropped by one-third. Eighty percent of all auto negligence lawsuits have now been eliminated in New York, and rate increases have averaged less than 5 percent a year since 1978.

Descriptive thresholds are superior to dollar ones. Yet, among the 23 jurisdictions (including the District of Columbia) with no-fault laws of some type, only Michigan, New York, and Florida have them. Thirteen other states have dollar thresholds, ranging from \$200 to \$5000. And in seven states, no-fault benefits have simply been superimposed on an unchanged tort-liability system. These are called "add-on" states.

What makes a bad law?

In all no-fault states, the number of lawsuits has dropped, but in most of them it hasn't dropped enough to pay for the new no-fault benefits. Classic examples: Pennsylvania and New Jersey.

Pennsylvania's law gave victims unlimited medical and rehabilitation benefits, but permitted lawsuits if victims had \$750 worth of medical expenses. Result: Too many victims could collect under both fault and no-fault for the same injuries. "We had two systems. One the fault, and the other no-fault, so it shouldn't be terribly surprising it became very expensive," says Jonathan Neipris, Pennsylvania's deputy insurance commissioner.

Premiums for personal-injury and liability coverages in Pennsylvania have been rising about 20 percent a year since 1975. After several years of trying to fix Pennsylvania's law and running into snags every step of the way, the state legislature decided earlier this year to eliminate all restrictions on lawsuits and become an add-on state.

New Jersey's problem was similar. Its no-fault law provided for unlimited medical benefits, yet it allowed lawsuits if victims accumulated only \$200 in medical bills. The tort liability system continued to operate virtually unchanged. Insurance rates shot up. Premiums in New Jersey are sometimes double those in Detroit for comparable coverage. Of course, many factors influence rates, but there's little question that New Jersey's have-your-cake-and-eat-it-too no-fault law contributed to high premiums there.

Paying victims, not lawyers

Car owners get more value for their premium dollars under no-fault than they do under the tort system because more of each premium dollar is paid out in bene-

fits to auto-accident victims.

Before no-fault was passed in New York, the Department of Insurance estimated that about 18 cents of every premium dollar was paid as benefits to accident victims. The Department now estimates that approximately 40 to 50 cents goes back to victims, to pay for such things as medical care and rehabilitation. Much of the premium dollar still goes for insurance-company expenses, but less money now goes for litigation.

A recent DOT study found that the average no-fault state returns in benefits a little more than 50 cents out of every dollar. Michigan, which provides the greatest benefits, returns 53 cents.

The DOT study also found that about twice as many victims (per 100 insured cars) are being compensated under no-fault than under the tort system. No-fault is compensating more victims even in states with the lowest benefits.

And benefits are paid quickly. Most laws require companies to pay victims

within 30 to 60 days after they submit proof of their claims. By contrast, in tort states victims have to wait months or even years to win compensation.

Some proponents had argued that no-fault would cause auto-insurance premiums to fall. It hasn't happened. In the better no-fault states, premiums have risen about as much as in tort states.

The more thoughtful advocates of no-fault are neither surprised nor greatly disappointed that no-fault hasn't cut premiums. No-fault policies are paying the medical benefits of many people who formerly would have gone uncompensated. And the cost of health care has been rising fast.

The seriously injured

Good no-fault states offer something for the seriously injured that the tort system cannot offer—fast rehabilitation therapy. By the time the tort system comes forth with an award, it may be too late for rehabilitation to do much good

for the seriously injured person. No-fault benefits paid quickly encourage rehabilitation when it's likely to be most effective, as it was in Faith Ann Glynn's case.

In the no-fault states with unlimited medical and rehabilitation benefits, the results of early rehabilitation are dramatic. For example, the Automobile Club Insurance Association in Michigan, a major auto insurer in that state, recently had 923 cases of catastrophically injured victims on its books. Of those, only 15 were in nursing homes.

An insurance-industry group recently studied 420 seriously injured auto-crash victims in the three states (Michigan, New Jersey, and Pennsylvania) with unlimited medical and rehabilitation benefits. More than 80 percent of them had been in rehabilitation programs—which often are not covered by health insurance—and most had benefitted from them. Most were living at home and many had near-normal life expectancies.

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What's the deal with no-fault auto insurance?

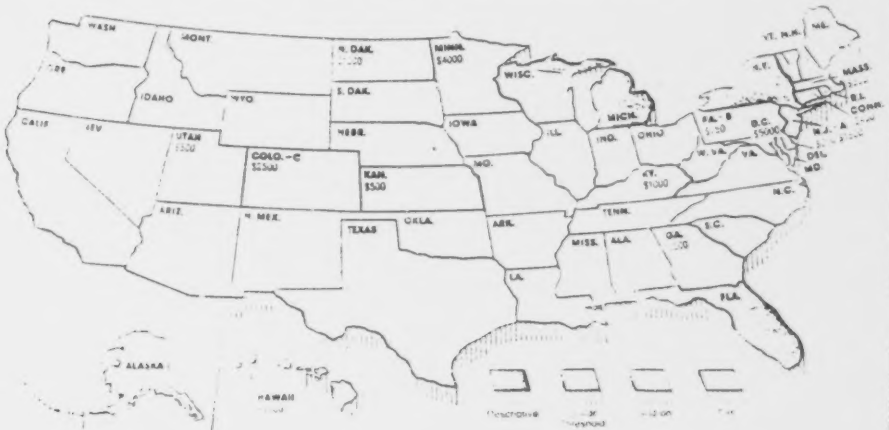
The map below shows the kinds of auto-insurance laws that prevail in the 50 states and the District of Columbia.

A state with a descriptive threshold allows victims to sue only if their injuries are serious. Their heirs can sue in the event of their death.

A state with a dollar threshold allows victims to sue if they accumulate medical bills that exceed a specified dollar amount. The map shows the thresholds for each of the 13 jurisdictions that use this arrangement.

An add-on state does not restrict the right to sue but requires insurance companies to offer no-fault coverage to car owners. In three of these states—Delaware, Maryland, and Oregon—car-owners are required to buy it.

A tort state does not restrict the right to sue. Accident victims usually receive no compensation for their injuries from their own auto insurance. They must make a claim against the other person's insurance company, or sue the party they believe caused the accident.



1 = New Jersey recently changed its law, giving drivers the option of a \$200 threshold or a \$1500 threshold.

2 = Pennsylvania, effective Oct. 1, 1984, is eliminating restrictions on the right

to sue, making it an add-on state. Also, companies will no longer be required to offer unlimited medical benefits.

3 = Current threshold is \$500. \$2500 threshold takes effect Jan. 1, 1985.

No-fault insurance

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The recent DOT report concluded: "In the absence of high-benefits no-fault auto insurance, there probably would not have been enough money available for the treatment of the catastrophically injured . . . to produce any significant improvement in the condition of any of these victims."

To get major help for the seriously injured, only a true no-fault statute with high benefit limits will do. A no-fault state with skimpy benefits is almost as bad as a tort state from the standpoint of helping the seriously injured victim. An insurance-industry research group surveyed one group of catastrophically injured crash victims and determined they needed, on average, more than \$400,000 for lifetime care and rehabilitation.

A stalled crusade

Since the mid-1970's, only the District of Columbia has been able to pass a no-fault law. The no-fault movement has been stalled primarily by trial lawyers, who have fought vigorously to obstruct passage of good no-fault laws and to weaken or repeal existing laws.

In 1976, the lawyers gave a quarter of a million dollars to Congressional candidates who opposed or might oppose no-fault. Two years later, the American Trial Lawyers Association succeeded in blocking a bill that would have set Federal standards for state no-fault laws.

More recently, no-fault legislation has been debated mainly at the state level—and trial lawyers have been effective in influencing state politics. Recently, they've been at work in Kansas. This year the Kansas legislature approved an increase in no-fault benefits from \$2000 to \$5000 and an increase in the threshold from \$500 to \$1500, both modest improvements. But Governor John Carlin, who has received significant campaign contributions from several trial lawyers, vetoed the bill.

Trial lawyers were also instrumental in passing the law that eliminates restrictions on lawsuits in Pennsylvania.

While the lawyers labor against no-fault, the insurance industry is working for it—but not very hard. As Jean Huestand, vice president and general counsel for State Farm Mutual, says, "We think the principle is sound, but the storm has gone out of the issue."

A.A. has long supported the principle of no-fault laws. We hope to see them in the 28 states that still use the traditional tort system. But, equally important, we'd like to see the states that have half-hearted no-fault laws give the concept the chance it deserves. Where it has been implemented well, as in Michigan and New York, no-fault works. **1**

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WHATEVER HAPPENED TO NO-FAULT?

by Jeffrey O'Connell and Peter Spiro

Newspapers lately have been full of stories about the "liability crisis." Insurance company profits are falling, premiums are rising, and the industry and consumers alike are starting to panic. In New York City, the tram line from Manhattan to Roosevelt Island shut down because the company that insured it would not renew the policy. In Janesville, Minnesota, last year's Nativity pageant was canceled because insurance costs were prohibitive. In St. Anthony, Idaho, unaffordable insurance premiums closed down the city office building, the public library, the senior citizen center, and the snowplow service.

The liability crisis has inspired much debate about whether the enormous volume of litigation that accounts for much of the high cost of insurance ought to be restricted. Unfortunately, the question of whether to limit the right to sue can be frustratingly muddy. Do we really want to ease the pain felt by manufacturers of drugs that cause birth defects? Should architects and engineers who design buildings that collapse avoid responsibility?

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But if the liability crisis as a whole seems to defy simple solutions, there is one substantial chunk of it that does not: automobile accident cases. In state courts around the country, automobile-related lawsuits often account for more than half the case load, driving up auto insurance premiums, delaying benefits for accident victims, and devouring dollars that might be spent compensating serious injury. Rather than spend time and money arguing in court about who is at fault when two cars happen to collide, as cars inevitably do, why shouldn't insurance companies automatically pay out benefits to any policyholder who suffers in a traffic accident, no matter what the circumstances?

This idea, of course, got a lot of attention during the 1970s under the name of no-fault auto insurance. Massachusetts passed the first no-fault law in 1970. Twenty-three other states followed suit. There even was an effort in Congress to establish no-fault nationwide. But you don't hear much about no-fault these days. When you do, the news is usually that some state government has lost faith in it. No new states have been added to the no-fault roster since 1975, and Nevada, Pennsylvania, and the District of Columbia, have

repealed it. Conventional wisdom seems to be turning against no-fault as yet another starry-eyed liberal reform that failed.

But if no-fault is to be judged a failure—and we think it shouldn't be—the problem lies not in the idea but in its half-hearted execution. Even where no-fault has been tried, the fault-based tort system that no-fault was meant to replace usually has remained relatively unthreatened. No-fault statutes have not gotten enough victims of automobile accidents out of our courts because the lawyers won't allow it.

No fault, no fee

The case for no-fault was and remains simple and compelling: the traditional, tort law process of fault-finding gobbles up time and money that could be spent compensating people who need help. Under a pure tort system, if a driver suffers injuries from a car accident, he is not automatically entitled to compensation from his insurance company. Before he can collect, he must demonstrate to a jury that another driver was responsible for the accident. If the victim wins, the wrongdoer (actually, the wrongdoer's insurance company) must pay him not only for his out-of-pocket expenses—medical costs and the loss of wages—but also for the "pain and suffering" that results from the injury. If he loses, he gets nothing.

In contrast, under no-fault, an accident victim does not need to prove that anyone was at fault before he gets his money. A no-fault policy insures against *any* circumstance that might injure a driver. The harm might come from another driver; it might also come from the victim's own carelessness, a situation the tort system cannot address. Consider a collision with a stationary object. If you crash into a tree, you'll have a hard time convincing a jury that it ran out into the middle of a road. (Anyway, trees tend to be insolvent.) Or consider a collision with another driver that injures the driver who caused the accident. Under the tort system, if you're at fault you can't collect.

And what about the broad gray area in which most traffic accidents occur—cases where both drivers are at fault? Maybe one fellow was speeding because he was a little anxious about being late for an important business meeting. Maybe the other was looking out the window at an attractive woman who was crossing the street. The tort system's usual solution is to have the two men slug it out in court over who was more guilty. Both men will be tempted to distort the truth in

order to collect; moreover, if the jury concludes that both were negligent, both men may be losers—neither may be compensated for injuries. Under no-fault, the question is irrelevant.

The difference no-fault can make in the lives of auto accident victims was illustrated dramatically by two cases cited in a 1984 issue of *Consumer Reports*. In Illinois, which operates under the tort system, 25-year-old Robert Demichelis was returning home from a basketball game at Northern Illinois University when he dozed off at the wheel. His Datsun 200SX bounced off a guard rail and smashed into a concrete divider in the middle of the interstate. Demichelis's head struck the windshield, and he suffered brain damage. His ability to reason and make judgments was sufficiently impaired that he was unable to hold a job. Health insurance covered his medical bills, but his family ended up paying for his rehabilitation treatments. At the time the article appeared, Demichelis's family had paid out \$15,000. Because they had no one to sue, there was no auto insurance money to cover the cost.

The second case took place in Michigan, which has the best no-fault law in the country. Thirteen-year-old Faith Ann Glynn was riding her bicycle when a car struck her from behind. Glynn, like Demichelis, suffered brain damage. In addition to having two brain operations, she lived in nursing and rehabilitation centers for two years. But in Glynn's case, the automobile insurance company that covered the entire family picked up all her medical expenses. It didn't matter that Glynn hadn't been driving a car; their coverage extended to auto accidents that occurred when a member of the family was walking or riding a bicycle.

Of course, if Faith Glynn had been injured in a state operating under the tort system, she would have been able to sue the driver. But, practically speaking, tort awards are limited by the extent of the wrongdoer's liability coverage, which most states set at a minimum of no more than \$10,000 or \$20,000. (Glynn's medical bills and rehabilitation treatment, all paid by her auto insurance, came to more than \$180,000.) While it's true that most people take out insurance in excess of the minimum, there's no guarantee that the fellow who crashes into you will have—and, under a tort system, it's the other guy's coverage that determines how much you collect. No-fault, by contrast, removes this anxiety, since what matters is not someone else's coverage but your own. And that coverage can be more generous because of money saved by avoiding the courtroom. (Largely

With the repeal of no-fault auto insurance in Nevada, Pennsylvania, and the District of Columbia, conventional wisdom seems to be turning against it as yet another starry-eyed liberal reform that failed. But where we really failed was in allowing lawyers intent on protecting the costly tort system to water down no-fault.

thanks to lawyers' fees, only 44 cents of every dollar paid into liability insurance pools makes it into the pockets of accident victims.) This is not to say that no-fault is prone to granting extravagant awards. For one thing, no-fault does not reward on the basis of "pain and suffering." No-fault also caps recovery for lost wages and often subtracts compensation made to the victim under other insurance programs. Most important, payments are disbursed as medical and other bills fall due and not in the sort of speculative lump sums that make trial awards resemble a grotesque sweepstakes.

Crossing the threshold

If no-fault's virtues are so obvious, why are states now turning against it? We can begin to answer this question by looking at the half-hearted way most no-fault legislation has been drafted. Most states have chosen to water down the no-fault principle in one of two ways.

The first is to set thresholds that must be reached—most commonly, medical expenses in excess of a certain dollar amount—before an injury victim may bring legal action. The states that have adopted this form of no-fault—16 of the 24—are called "no-lawsuit" states. This is a serious misnomer. Lawsuits are routine in many of these states. The dollar threshold for medical expenses is as high as \$4,500 (Minnesota) and as low as \$200 (New Jersey). Obviously it doesn't take much of an injury to come away from the doctor with a \$200 bill. And even when the dollar threshold is high, doctors with an eye on the "pain and suffering" jackpot, which typically pays off at three to five times the amount of real economic loss, may be tempted to pad costs. (One doctor charged with cost-padding was the proud owner of a yacht called *Whiplash*.)

A better way to set thresholds is through categories of harm—for example, those who have suffered permanent disability, serious disfigurement, or the loss of a limb. These "verbal" thresholds tend to be more restrictive than

monetary thresholds, with the result that the verbal threshold no-lawsuit states—Michigan, New York, and Florida—end up having, well, fewer lawsuits.

The second method of watering down no-fault is to place no restrictions at all on the right to sue and merely to require insurers to sell, and in some cases drivers to buy, no-fault insurance. Eight of the 24 no-fault states have adopted this form of no-fault, including Texas, Maryland, and Oregon. In these "add-on" states, no-fault is watered down even more than in the no-lawsuit states, since the courts remain open to all accident victims.

In both the no-lawsuit and the add-on states, there is an additional problem: insurance companies are required to offer only a limited amount of no-fault coverage—in some states only a few thousand dollars. This leaves anyone with a serious injury no choice but to resort to the courtroom. An exception is Michigan, which enacted no-fault in 1975. Michigan is a no lawsuit state with a tough verbal threshold: only accident victims who can show that they have suffered "serious impairment of the bodily function" or "permanent serious disfigurement" have access to the courtroom. (Families of those whose injuries result in death may also sue.) By saving on court costs, Michigan is able to offer unlimited no-fault medical benefits; there is no cap on what victims like Faith Ann Glynn can collect from their insurer. At the same time, Michigan enjoys low auto insurance premiums: in 1983 the U. S. Department of Transportation found them to be 17 percent lower than they would have been had no-fault not been enacted.

Auto didacts

Why the compromises that have proven so damaging everywhere but Michigan? Blame a small group of self-interested professionals who see a serious threat in the passage of tougher no-fault laws. Most of the nation's trial lawyers earn their bread and butter through tort law; fees for

auto accident cases alone top \$1 billion annually. Obviously these fees are threatened by no-fault. While upwards of 80 percent of all tort cases—and certainly *all* high-stakes tort cases—require the services of a lawyer, only 15 percent of all no-fault claims do (usually for dealing with the insurance company). True no-fault would bring that 15 down closer to zero. Small wonder, then, that the lawyers have done everything they can to strangle no-fault in the crib.

The Association of Trial Lawyers of America annually doles out hundreds of thousands of dollars in political contributions, aimed primarily at issues related to tort law, including no-fault. ATLA can take much of the credit for the defeat of a bill before Congress in the late 1970s that would have required states to adopt no-fault laws with minimum coverage of \$100,000 for medical expenses and \$24,000 for rehabilitation. Equally important have been local groups operating at the grass-roots level, like ADOPT (Attorneys Devoted to Ohio People Totally), which targeted state legislators who favored no-fault.

Lawyers have an additional advantage in manipulating the system because they tend to be active in political campaigns. Consider the experience of one 1972 Democratic candidate for governor in a major northeastern industrial state. "In community after community," said one key aide, "we checked and found that plaintiffs' lawyers were campaign or finance chairmen. . . . They would not have tolerated a pro-no-fault stand. Our organization might well have fallen apart." Unlike, say, steelworkers, trial lawyers can organize their time schedules by obtaining continuances past election day; indeed, in election years, from November 15 on, trial calendars frequently are jammed and most courthouses look like Grand Central Station. Lawyers are also vastly overrepresented in state legislatures across the country. The brotherhood of the bar obviously is felt when it comes time for a roll call.

Of course, the trial lawyers insist that more is at stake than their own self-interest. "We don't give a damn what the cynics say," says one former ATLA president. "We want our views debated not on who represents them but on who they affect, and that's our clients, the consumers." The argument runs something like this: 1) the great common-law tradition guarantees victims their day in court; 2) by taking cases on a contingent-fee basis, whereby an attorney is paid nothing up front but instead works for a percentage of any trial awards, plaintiffs' lawyers assure that worthy claims will be prosecuted; 3) "pain and suffering" constitutes an important and real part of

loss and should be accounted for in determining appropriate compensation; 4) by punishing drivers who do things we don't want them to do, the tort system deters socially detrimental behavior; 5) contrary to supporters' assertions, no-fault actually increases auto insurance premiums.

Let's set aside 1) and 5) for the moment. The problem with 2) is that contingency fees typically swallow up a third of any jury award; some lawyers go as far as to charge 50 percent. Even assuming this incentive system is fair, it does nothing to help those whose injuries come about because of their own fault (the fellow who runs into a tree or into another driver) or those who suffer in an accident where fault is not easy to assign (the fellow late for an appointment who runs into the fellow daydreaming about the woman). Indeed, the tort system makes the latter case worse since the need for each party to prove the other unambiguously guilty contradicts the legal standard for going to jury in a civil case in the first place—a set of facts about which reasonable men may disagree.

As for 3), the "pain and suffering" endured by the victim of any accident is difficult to translate into a dollar figure; indeed, the worse the suffering, the more sadly inadequate monetary compensation of any kind seems. And what about the "pain and suffering" endured by accident victims like Robert Demichelis who can't blame their fate on someone else? Should their economic needs go unmet while we grope to meet the less tangible needs of others? If we are going to spend money on people who are suffering, shouldn't we put a priority on addressing problems we can solve, like unpaid medical bills?

Moving on to 4), the punitive effect of the tort system is undermined by the fact that almost all court awards are covered by a wrongdoer's insurance, with the result that a negligent driver will feel the brunt of his sins only marginally in the form of hiked insurance premiums. Not surprisingly, comparisons of fault and no-fault jurisdictions show no statistically significant difference in the number of accidents. In the case of the criminally reckless driver, the proper solution is vigorous enforcement of criminal laws. If a drunk or excessively careless driver poses a serious menace to society, he ought to lose his driver's license or even go to jail.

The arguments that carry the most weight with the public, legislators, and state judges are those based on the "right to sue" and the alleged higher cost of no-fault. Local courts in Washington, D.C. and Florida have declared threshold requirements unconstitutional insofar as they discrim-

The example of Michigan shows no-fault can work. By restricting courtroom access only to victims who suffer serious injury, Michigan is able to offer unlimited medical benefits while enjoying premiums that are 17 percent below what they'd be under a tort system.

inate against some claimants' opportunities to collect damages for "pain and suffering." (The issue is now moot in D.C., where the city council recently gutted its no-fault statute.) Although several consumer groups, including the Consumers' Union, the nation's largest, have come out squarely behind the expansion of no-fault, other consumer advocates—most notably, Ralph Nader—have avoided the issue, most likely because it conflicts with the notion that the right to a day in court is fundamental to keeping misbehavior in check. This is certainly true when General Motors is building Corvairs that are killing people; we wouldn't want manufacturers to escape liability for products that cause the rest of us serious harm. But the case of the lone driver, whose limbs are as much at risk as those of whomever he hits, is qualitatively different. Moreover, the success of no-fault in Michigan shows that a tough no-fault law can still leave room for those with the greatest claim of "pain and suffering" to go to court and receive additional compensation for serious disfigurement. Such people may deserve special treatment in our society, and a properly written no-fault law can accommodate them.

In addition, there's a precedent for denying court access to potential tort claimants as long as they are granted other benefits in return: worker's compensation. Worker's comp laws deprive employees of the right to sue employers for injuries occurring at the workplace but do guarantee victims adequate, if not particularly extravagant, compensation regardless of questions of fault. All 50 states now have such statutes, and imperfect though they may be (see "Adding Insult to Injury," Teresa Riordan, March 1984), nobody is suggesting a return to fault-based in that area.

As for the cost problem, it is true that car owners in some no-fault states have seen substantial increases in their insurance bills. This has been the primary reason for the repeal of no-fault laws in Nevada, Pennsylvania, and the District

of Columbia. But inflated premiums are only the logical result of introducing no-fault without correspondingly restricting the right to sue. No-fault proponents have never pretended that you could save money unless access to courts was severely restricted. And, in fact, in the states with restrictive verbal thresholds—Florida, Michigan, and New York—insurance rates have been less than they would have been had no-fault not been enacted.

In spite of all the compromises, it's worth noting that even watered-down no-fault laws can claim success on several fronts. According to the Department of Transportation, no-fault compensates more people (roughly twice as many) with greater benefits (79 percent more) in quicker payments (almost all no-fault payments, as opposed to only half of all tort awards, are made during the first year following injury). No-fault also has benefited taxpayers: while no-fault hasn't reduced lawsuits as much as it should have, thousands of accident-related small claims have been kept out of court. Since the average jury tort case costs the taxpayers \$8,300, those thousands of cases add up to millions of dollars saved. To cite just one example, during the four years before no-fault was enacted in Massachusetts in 1971, the average number of automobile accident tort cases annually was nearly 32,000; during the four years that followed enactment, that average dropped to 12,000.

There is one last benefit no-fault might bring to our society: it might cure us of the habit of minimizing our own fault and maximizing that of others. There is something depressing about a process that encourages people to behave suspiciously at best and dishonestly at worst. Lawsuits over automobile accidents, where frequently both drivers were somewhat at fault, are forums where the tendency to lie is particularly strong. Even the most public-spirited among us can find ourselves subtly distorting the truth in the courtroom. It isn't worth the queasy feeling that results. Let's give no-fault another chance. ■

PRELIMINARY REPORT

GAPS AND PROBLEMS IN INSURANCE COVERAGES

Submitted By

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1/23/86

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PRELIMINARY REPORT

GAPS AND PROBLEMS IN INSURANCE COVERAGES

As a Subcommittee of the Insurance Task Force, our charge has been to develop a White Paper that can be utilized as the official position of the National Head Injury Foundation. Our purpose as a Subcommittee is: (1) to review insurance coverages as they now exist for the head injured, (2) determine gaps and problems in coverages, and (3) propose recommendations to effectively augment and interpret policy provisions in the most advantageous way to address the needs of the head injured.

As a preface to the discussion of this particular topic, it would be helpful to identify the approach we have taken as our general format, first by identifying the dichotomy within the insurance industry. These include the Casualty Insurance Industry and the companies that comprise the Accident and Health field. The Casualty Insurance Industry represents those companies writing Workers Compensation, along with Auto Liability and Auto No-Fault. Accident and Health carriers write short and long term disability, as well as health insurance.

The Casualty Companies' exposures to loss are usually statutory in the sense that each state enacts legislation that clearly defines the necessary policy provisions and mandated benefits. The Accident and Health Companies' liabilities are a contractual relationship between the individual company and their insurer. Keep in mind that all of the types of insurance we will discuss can also be self insured, providing the individual or company meets the financial responsibility requirements.

A GENERAL REVIEW OF INSURANCE COVERAGE
AS IT PERTAINS TO THE HEAD INJURED

Workers Compensation Coverage

This form of insurance is usually purchased by an employer without financial contributions by employees. Its purpose is to provide statutory defined benefits in exchange for a limitation on an employee's right to sue for compensatory damages. Benefits include disability benefits providing for loss of income, and medical benefits. Some states provide specific rehabilitation benefits targeted toward vocational rehabilitation and survivor benefits for the spouse and children in the event of the employee's death.

To be eligible for Workers Compensation benefits an employee must meet three criteria:

- 1) the employee must be working in a covered employment setting under the jurisdiction of the workers compensation laws
- 2) disability must be compensable in nature
- 3) there should be a causal relationship between the employment and the disability

Payment criteria, as it pertains to medical and rehabilitation services usually hinges on a "reasonable and necessary medical treatment" test. Taking existing medical documentation along with the type of service request made, the insurance carrier will then decide whether they will authorize the care. From the medical standpoint, the carrier's exposures are in most states unlimited in dollar maximums, as long as the medical treatment is warranted as a result of the accident.

Auto No Fault and Liability Systems

With the development of Auto No Fault systems in the early 1970's came increases in minimum limits for auto liability coverages. Both types of coverage are combined here, since they arise out of the exposure of driving an automobile. No Fault benefits are on a first party basis, whereas, Liability is a third party benefit.

No Fault benefits are paid through the individual's own insurance company, regardless of fault or tort liability. Benefits will usually include medical, indemnity or lost wages, and funeral or survivor's benefits in cases where the accident results in a fatality. The No Fault concept was designed to provide prompt payment for lost wages and medical expenses as they are incurred, and to eliminate long delays in recovering economic losses in a tort liability system. Early rehabilitation has proven to be more cost effective in achieving better outcomes. Benefits are provided not on pain and suffering criteria, but rather in economic terms based on medical expenses and lost wages.

Each of the states that currently have enacted No Fault statutes provide for different levels of benefits. New Jersey and Michigan are the two most progressive states in providing unlimited medical coverage. Lost wages in all the states currently under No Fault are capped. As under Workers Compensation, medical benefit payments are contingent on the "necessary and reasonable" test.

Liability coverages as they pertain to automobile accident victims provide for compensation resulting from negligent acts or civil wrongs of the insured operator for injuries to innocent third parties. Minimum liability limits start at \$15,000 per person injured. These minimums are woefully insufficient when dealing with a catastrophic injury, such as brain injury.

Accident and Health Insurance

This is a group type of insurance purchased primarily by an employer for the benefit of their employees, and their employees' dependents. Coverage may also be written on an individual basis. Employers provide benefits on a contractual basis for their employees, who may also bear a certain percentage of the cost. These policy provisions represent the level of risk an employer is willing to assume. Very often, the larger the employer, the more generous the benefit plan. Some labor unions have played an important role in negotiation involving employee benefits.

Policy provisions will usually incorporate a basic plan, along with a Major Medical component. Not only will a policy contain an aggregate limit from anywhere between \$25,000 to \$1,000,000, but also inside limits such as specific number of hospital days, skilled nursing facility days, or limits on the number of therapy sessions.

New forms of payors are entering the markets, such as Health Maintenance Organizations (HMO), and Preferred Provider Organizations (PPO). These groups blur the distinction between providers and reimbursers. Not only are they bearing the risk of treatment, but they also make arrangements for provision of treatment. These new players represent approximately 7% of the health insurance market. Stress is placed on preventative care and the execution of contracts for care with the most cost efficient providers. This is an organized system of health care that stresses a high healthy/sick ratio that allows them to compete with traditional third party payors.

Short and Long Term Disability

This form of Accident and Health coverage looks at injury or illness from the perspective of lost wages exclusively. Usually a company will provide short term disability for an employee who cannot return to his former employment for a short period of time, such as 26 weeks. As the length of disability increases past the expiration of short term disability, the employee will be covered under long term disability for as long as he is unable to return to any type of gainful employment based on his education, background, and experience.

This form of indemnity coverage seeks to provide a portion of the employee's salary, i.e., 50 or 60% of his gross wages, keeping in mind that this form of injury or sickness must be non-work related.

DETERMINATION OF GAPS AND PROBLEMS IN COVERAGES

Workers Compensation

This type of coverage probably provides the greatest opportunity for the head injured to reach their maximum rehabilitation potential. Because of the nebulous criteria present in "reasonable and necessary" medical and rehabilitative services, the broadest interpretations are usually applied. Problems do occur based on individual company interpretations. There seems to be a predilection for utilizing medical opinions only from physicians. This can be detrimental to the head injured when higher level cognitive and executive skill functions are involved. Neuropsychologists and other therapeutic disciplines may at times be more adept at identifying and treating such problems.

Even within the same insurance company different claim representatives apply often inconsistent criteria for provider reimbursement. There may be problems in receiving and providing prior authorization for rehabilitation treatment or home care. This presents a level of risk to the provider. Uncertainty in reimbursement presents problems based on the intensity and high expense of treating the head injured as a disability group.

Carriers are oriented toward seeing dramatic progress in rehabilitation goals and meeting pre-determined time frames. If progress is not seen, this creates a skeptical attitude about the validity of future rehabilitation outcomes. Usually a carrier will feel that physical gains are sufficient in completing the rehabilitation process, ignoring any cognitive deficits that may still remain. Lack of general understanding is indicative of the claims industry in general, yet there are some companies that have an enlightened attitude as to the benefits of rehabilitation. Education that head injury rehabilitation is long term in nature is needed, as these clients may require life long support in dollar terms.

No Fault/Liability

No Fault generally follows the payment parameters we have already established in the Workers Compensation system. Unfortunately, only two states provide unlimited No Fault benefits over the lifetime of the head injured. Wage benefits are usually very limited in No Fault systems.

The Rehabilitation Nurse profession as it has developed, has aided the insurance community in understanding the greater issues involved with the head injured, and have a significant impact in general on the claims professional. However, some case managers in the field have not recognized that real cost savings in head injury are achieved not so much in the facility per diems in the rehabilitation phase, but in preventing the long term disablers in head injury; those being family system disintegration, and development of behavior problems and hospital recidivism.

Under liability systems the carriers have been slow to adopt proactive measures incorporating rehabilitation. Rather, the tendency is to negotiate and wait for a settlement prior to paying any monies for medical care. This results in a delay in initiating rehabilitation efforts due to lack of funding for programming. In addition, because of the very limited funding available on auto liability coverage, even if a settlement is consummated, the funds fall short of providing for the long term needs of the head injured. Attorney fees may be one-third of the settlement, which will reduce the net available for the future needs of the client.

Accident and Health Policies

To continue, we must point out that many of the ills we have discussed in Workers Compensation and Auto No Fault are present on the liability side as well. These will not be repeated in this section.

In the last few years, the insurance industry has recognized the benefits to be gleaned from individual case management. For a large proportion of the industry, head injury is not recognized as a specific diagnosis, different from the other medical groupings. In health insurance there are very significant problems that continue to exist in terms of licensure of providers. For example, most policies will pay for rehabilitation in a hospital accredited by the Joint Commission on Accreditation of Hospitals (JCAH), rather than using the standards for rehabilitation facilities set up by the Commission on Accreditation of Rehabilitation Facilities (CARF). This is so even when CARF is in a better position to evaluate rehabilitation facilities and programs.

Aggregate policy limits may be so low that long term rehabilitation efforts are thwarted. Very often, coverage runs out and the only recourse for families are State Medicaid Programs. Not only are there aggregate limits, but inside limits such as specified number of hospital days, or limits on skilled nursing facility days.

Rehabilitation gains for the head injured may occur more slowly, and therefore length of stay reviews, resulting in early discharge to less costly environments may be inappropriate, and actually delay further progress from occurring. Utilization reviews and criteria such as "medical plateau" in recovery may be prematurely applied.

Some policies limit treatment to certain types of rehabilitation such as physical therapy, or speech therapy. These policies preclude access to other valuable types of care that the head injured require, such as occupational therapy, psychology, and recreational therapy.

As the clients progress and require community re-entry programs for skill development in cognitive and socialization areas, some policies may not recognize these types of care. Sometimes these areas may be considered educational or psychiatric in nature, and therefore are completely excluded, or severely limited. The development of alternate sites for rehabilitation, such as skilled nursing facilities and other functional environments have not at times been considered.

Maintenance care is very often needed in the home for those, who because of judgement problems, require that they cannot be left alone. This occurs as a progress orientation is applied to the home environment, and this form of care may only require attendants, and not medical professionals.

RECOMMENDATIONS FOR CHANGE

It is of course realized, that throughout this report generalizations have been made in all areas. We do recognize that there are a number of very forward thinking companies that are extremely progressive in their approach to these payment issues. Many of the following points are based on existing programs that have been very successful in providing for the long term needs of the head injured.

Catastrophic Riders

This addition to current policies could be offered by insurance companies to their policy holders for an additional premium. Services that are currently excluded in the original policy, but that are very necessary for the head injured could be added. Such items as home modification, provision of rehabilitation in alternative settings, and maintenance or attendant care could be included. The additional premium would take into consideration that catastrophic injuries are a small percentage of the incidence of health insurance claims.

Common Sense Approach

We would advocate increased use of individual case management systems, that are not only cost effective, but provide the most appropriate types of care based on the needs of the head injured client. This allows for provision of extra contractual types of services in environments not considered in the policies. This system has been utilized in casualty insurance for years, and is now being applied by the larger group carriers. This is a very favorable development for the needs of the head injured and hopefully more of this will occur in the future.

Enhanced Educational Efforts

Addressing the Problems of the Head Injured

Increased awareness through the patient advocacy efforts of the National Head Injury Foundation have helped to focus attention on this problem. The effectiveness of the group at both the state and federal government levels have already demonstrated significant results. Employee benefit managers and high ranking officials at the corporate level must begin to understand the issues and consider various funding alternatives.

Cooperation Between Providers,

Payers, Regulators, and Consumers

Each of these four groups has a significant impact in decisions affecting this disability group. Rather than continuing the adversarial conflicts among these groups, we should direct our attention toward cooperation, and seeking out common ground. Areas of mutual interest and delineation of ways we can work together for the benefit of the head injured client are the real priority.

REPORT TO THE INSURANCE TASK FORCE
SUBCOMMITTEE ON REVIEW OF EXISTING INSURANCE COVERAGE
FOR THE HEAD-INJURED

by
Richard C. Schlotman

PURPOSE OF STUDY:

The assignment of this subcommittee is (1) to review insurance coverage as it now exists for the head injured; (2) to determine gaps and problems in coverage; and (3) to make recommendations for change in the coverage problem.

SCOPE OF THIS REPORT:

It was originally suggested that the committee divide its task and evaluate four different types of insurance-health, long and short term disability, workman's compensation, liability and auto no-fault coverage. As initial background, our study found, in general, that: (1) Custodial care is not included in most health insurance coverage; (2) Most short-term disability policies are sold to employers as temporary (26 weeks) protection for employers until Social Security is able to pick up coverage; (3) Custodial care and most other needs associated with rehabilitation are covered under the "liability" insurances, which are more closely responsive to the "tort" system of interpretation; (4) Workman's compensation is generally comprehensive, but individual states and individual companies interpret coverage--especially length and/or termination of coverage--in very different ways.

In trying to discover the attitudes toward rehabilitation in general and brain-injury in particular, and in trying to find out general themes of coverage, the common response from the claims departments of the carriers and the sales departments was, "we write and sell whatever the person/company needs and is willing to pay for." There were simply too many individual policies in existence to be helpful (without a data base and a computer program) to sort out main lines of coverage and trends in coverage. This was not the way to sample the field.

THE APPROACH/LIMITATION CHOSEN FOR THIS PRELIMINARY REPORT:

We pursued two different avenues to finding out what coverage and what gaps seemed to be appearing most frequently. The first resource was the providers of rehabilitation to the head-injured. Their successes and failures, if properly reviewed, could be a rich source of "experience with the claims people in the companies that they represent; who have a stake in securing coverage for their clients; and who are not company men/women" in the ordinary sense. They are advocates for the insurance company and also for their clients.

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This first resource, the providers, was difficult to assess since there exists on their part a lack of willingness to share their experience concerning insurance claims. The providers say they take this stance to protect their patients' confidentiality, but they also feel that the "insurance relationships" they have cultivated are very private and should only be for their organization's specific use. In other words, there is a wariness among the providers regarding the divulgence of coverage, insurance companies, problems, etc. that rivals the unwillingness/inability of the claims decision-making.

Because of the above limitations, this report confines itself to a survey of one agency and seven sets of brokers in three states and does not purport to be a complete or accurate sample. No information is available from primary hospitals or acute rehabilitation hospitals, except indirectly through the brokers' experience. Thirty-six insurance companies are represented, each having 1-6 head-injured patients with coverage in this sample. These companies are largely those handling health insurance and workmen's compensation policies. Only five liability and no-fault carriers are included. No long or short-term disability policies are included.

Companies are not named specifically, and the types of coverage and gaps for each type of insurer are not separated out. Indeed, there were no differences, among the cases we examined, except those mentioned above.

DATA ON COVERAGE

P.T.	O.T.	Psych	S&L	Voc	Cust Care	Resp Care
36	16*	28**	15	5	4***	4***
Psychiatry		Neurology		Rehabilitation Nurse		
36		36		32		
Residential Care		Transitional Living		Home Care		
10****		***		30 (sixty visits per year.)*****		

- * 20 companies in total when special exceptions and definitions are made and accepted.
- ** In 18 of these policies the cap was \$1500; in 3 of these the cap was \$1000 or less. In 17 of these policies, the coverage was 50% or less; 2 involved in extra-contractual arrangements.
- *** Extra contractual arrangements (2)
- **** In skilled nursing facility.
- ***** Insurance company rehabilitation nurse managed program made it possible for four of these situations to be extended up to one year.

PROBLEMS ENCOUNTERED (GAPS?)

Some of the problems listed below are general, across-the-board claims problems. Some are experiences which may indicate trends. Others are instances which occur in sufficient frequency as to be problems in providing service to the head-injured, but which probably do not represent company philosophies. These latter are probably the problems encountered by working claims agents with little time and experience and the supervising claims managers who hear the words "cost-containment" from higher levels of the company but are not offered opportunities to learn about short-term/long-term cost-containment relationships.

In other words, we have no hard indictment of either specific companies or the over-all insurance industry. We suspect further study would show there to be an equal blame apportioned between the providers inability to learn the system and communicate within it effectively and the patients inability to seek the advocacy and information needed to secure their contractual rights.

The following are "experienced problems" to securing coverage for the brain-injured person in such a way that effective and timely rehabilitation may take place:

1. In all insurance companies, there is difficulty in securing prior authorization for treatment, even verbally; and it has been impossible to gain written approval prior to the onset of the intensive treatment process. This means that the insured and the provider take significant financial risks ^{as well as} ~~of~~ the risks of regression and loss of motivation. Claims agents assure us that they will not put approval in writing and will authorize payment only when they see the bill.
2. Some therapies, such as Occupational Therapy and Psychological Therapy, have such out-moded or poorly understood definitions in the insurance industry that they are often not covered in the "specialty" name, but are covered in the "modality" of treatment. That is to say the coverage excludes the profession rendering the service but includes the modalities which that specialty renders. Insurance claims agents have often said to providers, "If that is what an Occupational Therapist does, then bill it as Physical Therapy, and we will pay for it." An ethical provider's response must be "It is the insurance company's problem to redefine the profession according to up-to-date usage and practice; do not expect the provider to fraudulently misrepresent its treatment."
3. Insurance companies are putting limits on Psychological Therapy or are using percentages of charges that make it impossible to give significant coverage in this important area for the brain-injured.

It seems that it is again the modality of treatment that should define the particular needs of this patient population (by diagnostic category) rather than the sweeping generalizations of what constitutes psychological treatment. Psychology for the neurologically impaired is not the same as that given for the various "mental and nervous conditions".

4. Persons in the insurance companies who are designated to authorize or are informed about catastrophic claims and extra-contractual possibilities are not readily known or available to the general claims agent or provider.

5. The delays in authorization and/or payment are extremely damaging to the head-injured family and patient. It appears that this delay is not recognized as important by the insurance companies, nor as relating to timely and necessary treatment.

6. There appears to be a trend, in cases where rehabilitation nurses and case managers are hired by an insurance company, for them to act as a rehabilitation "facility" in that they are doing more than insuring cost-effective, quality control of a case. They tend to act as program directors and professional providers. They also act as a central administrative person who farms out the minimum of treatment to various, uncoordinated community agencies. Under this unstructured, unprofessional program, patients progress slowly or plateau soon, so that termination is likely.

This is a disservice to patients, especially when they are not informed of their rights under the policy to more intensive, structured, and extensive rehabilitation and to the facility of their choice. In other words, some case managers appear to use the common denial mechanism on patients and their families to provide "a little physical therapy" with no insistence that cognitive and psychological deficits (for instance) be addressed. This has been done, at times, in spite of all professional recommendations to the contrary.

Such actions seem to undermine the efforts of the highly professional case managers and rehabilitation nurses, who are trying to insure quality and cost-effective service to head-injured persons. This must not be seen only to be an unintentional and infrequent occurrence. Indeed, this problem may be a trend that will increase as case management firms compete for the insurance industry's business with statistics of "results" in cost-containment that are short-sighted.

7. Companies that have (in their opinion) "gone extra-contractual" and "stretched their definitions" are reluctant to make this public or let others in their company (where there are similar cases within the company) become aware of their individualizing of coverage. Thus, within a company that has recognized the needs of the brain-injured in one case, there seems to be no communication nor interest in collecting data on the results of their good work. This data, therefore, does not seem to get into the system.

8. Insurance companies tend to look to standards which are arbitrary and/or traditional "Medicare-approved". There are lists of "O.K. providers", the standards of which are not available. Nor are there application forms that will open the doors to those lists for new facilities. Until standards are available for the industry, there needs to be an openness of approach, or at least open and available standards to be met, which are appropriate to this population of the head-injured.

9. The sixty-day home visit limitation is clearly inadequate in the case of the head-injured, no matter how loosely a "day" or a "visit" is interpreted.

10. In group claims situations, there seems to be a correlation between the size and the philosophy of the employer company towards insuring their employees and the nature of their coverage for the head-injured. Moreover, where the insurers are administrators of employers policies, both appear to be unwilling or unable to make decisions. The insurance administrators say they are helpless to negotiate coverage since the employers dictate the nature of coverage. The employers state they cannot work with the terms of coverage because it is a union/management negotiation problem with no flexibility.

11. The "adversary situation" between the insured and insurance claims personnel appears to be at its highest at the lowest levels of the company. At higher levels of the company, there is more understanding and acceptance of rehabilitation--as a cost-saving, exposure-to-future injury/litigation-saving necessity.

SUMMARY:

The above problems are stated as "problems". They are not necessarily "gaps in coverage". They become "gaps" as interpretations of role and coverage take place in the "give and take" of negotiation. They are brought forth at this time because they were reported as problems in providing third party payment for the brain-injured. These problems have resulted in loss of service, delays, regression, and litigation.

RECOMMENDATIONS:

1. This sample leads to the recommendation that a larger survey of insurers, brokers, providers, and family members be undertaken. Cooperation from insurers and providers will be more likely if a blue ribbon committee is appointed with congressmen, respected representatives of the insurance industry, and members of the Board of the National Head Injury Foundation. Dates for and collection of results may be in the hands of this subcommittee or another appointed group.

2. It is recommended that the Insurance Task Force propose to the NHIF that a statewide Board of Review be established by each state's NHIF. This Board shall serve as a non-partisan, non-provider stacked, insurance oriented, research oriented, informed, reviewing committee (with very general guidelines about acceptable modalities that are usual and customary).

Their purpose would be to consult with insurance claims personnel, family members, and providers as to the general modalities and treatment specialties appropriate to certain head injury conditions. The functions and methods of this Board of Review, as well as its' composition, need to be very carefully assessed.

Summer 1985

Catastrophic Health Insurance Coverage The Dilemma Of Economic Responsibility

By Kenneth C. Robinson, Controller
Cumberland, A Hospital for Children and Adolescents
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An irony of catastrophic insurance coverage today is that less is available as more is needed. This increased need is partly the result of the tremendous advances in medical technology, education and medical procedures. As patients with serious injuries and chronic illnesses live longer, the need for catastrophic insurance has grown. However, as the available insurance coverage is utilized, it becomes prohibitively expensive for employer groups to offer this coverage in the future. The same dilemma holds true for government funding through agencies, since just a few severe cases can exhaust an entire year's budgeted allocation for catastrophic care.

Cumberland recognizes this problem and considers it a challenge because we treat children and adolescents who are afflicted with serious chronic illnesses as well as psychiatric disorders. Twenty years ago, these patients would have had a poor prognosis but today they are living well into adulthood.

Another cause of increased insurance needs is the improved survival rate of children and adolescents suffering head injuries. These include closed-head injuries, primarily from motor vehicle accidents, but also diseases and carcinomas of the brain. In the past, these patients would have been placed in a nursing home or a psychiatric hospital, most likely a state facility. However, these children require more than traditional custodial care, and are not typical psychiatric patients. They need special and individualized treatment, including medical management, psychotherapy, physical therapy, speech and language therapy, occupational therapy and special education. To secure such treatment, these patients need some form of long-term funding from private insurance or government funds. Instead of increasing coverage, more and more employer group insurers are limiting the number of covered hospitali-

zation days and severely limiting the coverage for rehabilitation services. Although this coverage is seldom utilized in an insurance group, when it is used the care and resulting premiums are expensive.

In the case of injuries caused by motor vehicle accidents, a clear difference in funding exists between those states which require no-fault insurance and those which support the tort-liability system. Accident victims are more fortunate if they live in a no-fault state because this system provides for long-term medical and rehabilitation services immediately after the accident. In tort-liability states, the injured party must rely on health insurance, private funds, and/or obtain a court judgment against the other party. Even if a court judgment is obtained, by the time the lawsuit is settled and the award paid, the rehabilitation services may have been hopelessly delayed. In the case of single car accidents or if the other party has limited or no automobile liability insurance, a court judgment is a moot issue.

One of Cumberland's goals is to educate and convince insurers and government agencies about the increasing need for long-term medical and rehabilitation funding. Since the advent of prospective pricing for general acute care hospitals, many patients are transferred to custodial care facilities sooner and at a more acute level. The insurers must understand that these patients require more than low-cost custodial care. In fact, custodial care may even prove detrimental to a patient's long-term potential for improvement because the necessary intensive and "hands-on" therapies may either be delayed or not performed at all. What these patients need following discharge from the general acute care hospital is the opportunity to receive these extensive therapy services. The availability of long-term medical and rehabilitation funding would make such services possible.

In summary, the medical advances for chronically ill children and adolescents have far outpaced

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The Dilemma of Economic Responsibility

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public awareness and society's economic responsibility for them. This economic responsibility will improve if more states enact no-fault automobile insurance laws, more employee groups demand that catastrophic coverage be included in their group insurance policies and

government units plan for contingency funding requirements. The implementation of these and other economic proposals would assure adequate funding for long-term intensive rehabilitation. The need for such rehabilitation will only increase in the future.

The High Cost of a Bump on the Head

BY BRIAN T. McMAHON AND SUSAN M. FLOWERS

Detection, job modification, prevention are key components of worksite head injury programs.

Minor head injuries have longstanding effects that, if untreated, will take their toll on business as well as society at large. Consider the case of A.T., a 34-year-old, successful vice president in a major advertising firm, earning more than \$100,000 a year.¹ She was extremely intelligent, ambitious and responsible. On her way home from work late one evening, her car collided with a truck. As a result of the accident, A.T. suffered a mild closed head injury and was unconscious for about 20 minutes.

When the paramedics arrived, she was conscious, but dazed and confused by the blow. At the hospital emergency room, she was diagnosed as having had a concussion with no major complications. She was observed for a few hours and sent home with the admonition to abstain from work for a week or so.

Two days later, A.T. was back on the job, but was somehow not the same person. She did not know exactly what was bothering her so she played down her problems, which included fatigue and some cloudy thinking that affected her ability to make decisions involving important projects. In addition, she began to forget routine business related things.

When questioned about this behavior or challenged about one of her decisions, A.T. became increasingly upset and irritable. Four months later, the employer, not realizing any connection between her changed behavior and the accident, fired A.T. Six months after that she lost yet another job.

Unemployed, seriously depressed and now drinking heavily, A.T. was obsessed with devising ways to get

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her original job back. A neurological examination revealed that she was still remarkably capable and intelligent, in spite of subtle cognitive deficits. Nonetheless, A.T. would accept no other position involving a lower level of mental functioning and responsibility. Within a year she had two psychiatric hospitalizations, and remained unemployed and depressed.

This is just one of the estimated 3 million incidents of head trauma each year. Whereas many of these injuries are severe, leaving about 100,000 persons dead and 90,000 permanently disabled, the vast majority are termed minor head injuries. Over 70 percent of the people who sustain head injury are under the age of 35. Over 65 percent are injured as the result of a motor vehicle or sports accident, and the rest are hurt in falls or are victims of crime.

The Effects of Minor Head Trauma

As reported in the National Head and Spinal Cord Injury Survey conducted for the National Institute of Neurological and Communicative Disorders and Stroke, the cost of head trauma to society exceeds \$4 billion (in 1980 dollars) annually. This figure includes the direct expense of medical treatment, indirect costs of rehabilitation and support services, and the injured person's lost income. It does not reflect the additional costs incurred by business and industry, such as absenteeism or turnover.

Minor head trauma typically involves a loss of consciousness of less than 20 minutes, or a period of post-traumatic amnesia from 12 to 24 hours. In reviewing return-to-work studies involving workers hospitalized for minor head trauma, some interesting and unexpected findings emerge. Even 90 days after injury, one-third of these workers have not returned to work. Of those who have, some still have complaints concerning the aftereffects of the injury, including headaches, dizziness, personality changes, lethargy and irritability. Cognitive problems also may persist, including deficits in attention, concentration,

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information processing speed, perceptual and motor skills, and memory. Such difficulties typically reflect diffuse or generalized brain damage.

Nearly all minor head injured workers will return to work within six months, according to an annotated bibliography prepared by the Research and Training Center on Head Trauma and Stroke at New York University Medical Center. However, one-third of them will flounder in employment for years to come, meaning that previously stable employment histories will become checkered with multiple job changes, disciplinary problems and lowered level of responsibility.

Contrary to traditional medical opinion, the preponderance of recent evidence suggests that the injured person's physical and psychological complaints may reflect actual neurological changes in the brain itself. The severity of this phenomenon, termed post-concussion syndrome, also is dependent upon several factors including the person's psychological response to a disabling condition that is not well-understood, preinjury personality, and the underlying motivation for recovery and return to work.

Understanding Symptoms Important

In the work place, there are many aspects of a mild head injury that affect successful employment. Work proficiency, work rate, work quality, work endurance and the all-important work adaptive behaviors such as punctuality, attendance and understanding work rules are just a few examples. Personality problems, such as a lack of initiation, impulsivity or social isolation, also may emerge in the form of altered relationships with supervisors and co-workers.

For a production oriented employee, for example, a bricklayer or word processing operator, errors are noted quickly in the areas of work proficiency such as a misaligned brick or a paragraph in need of retyping. Managers or supervisors, on the other hand, can delegate to subordinates those tasks that have become difficult to handle. Thus, higher levels of employment often involve a greater likelihood of a strong support system that might allow for a period of gradual reintegration into the work routine with little disruption to status or performance, if there is an awareness and an acceptance of the limitations by all involved parties.

Thus, when an employee experiences a minor head injury involving even a brief loss of consciousness, the effects must never be minimized. Working cooperatively with the injured employee, employer and family, rehabilitation professionals can assist all concerned individuals in understanding that these behaviors are quite normal in the aftermath of a head injury. According to Lawrence F. Marshall of the University of California Medical Center of San Diego, recognizing and telling patients that they are not expected to function normally actually can get these people back to work earlier "because they are not suffering the frustration of returning to work thinking they are okay, and completely falling down on the job."

Whenever an employee experiences a minor head injury, a thorough evaluation and follow-up schedule should

be arranged. When an employer becomes aware of the injury, depending on the employer's services, internal corporate resources can be blended with those of community programs specializing in head injury. These programs should provide patient and family education regarding the aftereffects of head injury including referral to one of 300 local support groups of the Framingham, Mass., based National Head Injury Foundation, and referral for neurological and neuropsychological assessment.

Guidelines for Employers

Employers can offer a number of useful, specialized services through their employee assistance programs and corporate medical departments. Employers also can rely on head injury rehabilitation programs, preferably ones offering vocational services, or rehabilitation specialty facilities that include a categorical head injury program.

In either case, when a head injured employee returns to work, he or she should receive a thorough physical capacities evaluation and job analysis to provide a basis for the following additional interventions:

- Selective job placement, which requires reassignment depending upon changes in the employee's level of functioning;
- Job coaching to provide education and supervisory assistance during a prescribed period of work adjustment;
- Job modification or restructuring, which involves an alteration of the work environment or job duties to accommodate the altered status of the worker;
- Alternative work schedules, such as part-time employment, flextime or a compressed workweek to accommodate changes in endurance or scheduled rehabilitation activities, and to allow for an adequate period of rest and recovery.

Including the subject of head injury in corporate programs also makes good sense. At a minimum, employers can require seat belt use during business travel. Equally helpful would be organized support by industry for: protective head gear requirements; strict drinking and driving penalties; mandatory seat belt laws; air bags in automobiles; a 21-year-old drinking age requirement; restrictions upon the use of dangerous recreational vehicles; preventive measures in sports such as proper training and safety equipment; and the delineation of safe, designated areas for diving, cycling and other sports.

With each year, more and more serious head trauma cases are moving from the fatality category to the severely disabled category due to lifesaving measures that include improved evacuation and emergency room and neurosurgical procedures. Given the psychological, cognitive, family and employment problems experienced by all head injured persons, it is imperative that employers play a major role in prevention efforts. ■

Note

1. Michael Howard, Dallas (Tex.) Rehabilitation Institute, unpublished case study.

The CHAIRMAN. Our Committee will stand in recess until 10:00 o'clock tomorrow morning.

[Whereupon, at 1:28 p.m., the Committee was adjourned.]

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